

The Research Conference on HIV/AIDS Prevention, Care, and Treatment in New Jersey

SPONSORED BY

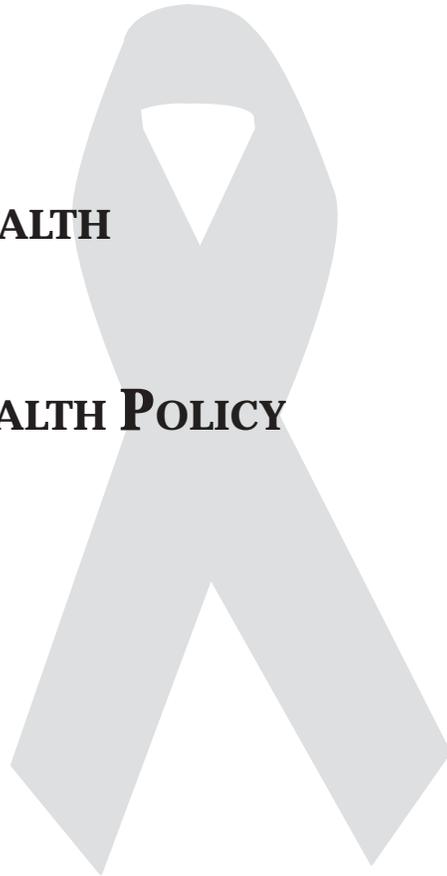
**NEW JERSEY DEPARTMENT OF HEALTH
AND SENIOR SERVICES**

AND

RUTGERS CENTER FOR STATE HEALTH POLICY

JUNE 14 & 15, 2001

NEW BRUNSWICK, NEW JERSEY



Division of AIDS Prevention and Control
P.O. Box 363
Trenton, NJ 08625-0363
609/984-5874



Rutgers Center for
State Health Policy

The Institute for Health, Health Care Policy, and Aging Research

Rutgers, The State University of New Jersey

317 George Street, Suite 400

New Brunswick, New Jersey 08901-2008

732/932-3105 Fax: 732/932-0069

THE STATE UNIVERSITY OF NEW JERSEY
RUTGERS

Table of Contents

Introduction to the Conference Proceedings 5

New Challenges for HIV Treatment Research in New Jersey and the Nation

Overview of the Epidemic-National Data 7

Tanya Sharpe, Ph.D.,

Epidemic Intelligence Service Officer, Centers for Disease Control and Prevention (CDC)

The National Perspective on Treatment Research 11

Katherine Marconi Ph.D., M.S.,

Director Office of Science and Epidemiology, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)

Overview of HIV/AIDS Epidemic in New Jersey and Ongoing Treatment Research Within the State 17

Sam Costa, M.S.

Director, Division of AIDS Prevention and Control, New Jersey Department of Health and Senior Services

New Challenges for HIV Prevention Research

Prevention through Peer Advocacy 21

Robert Johnson M.D., F.A.A.P.

Professor and Vice Chair of Pediatrics, Professor of Psychiatry, Director of the Division of Adolescent and Young Adult Medicine, University of Medicine and Dentistry – New Jersey Medical School

Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth 33

Anna Kline, Ph.D.

Director of Research and Information Systems, Division of Addiction Services - NJDHSS

Getting a Handle of Systems of Care: Access, Utilization, and Outcomes

***Assessing and Improving Medicaid Care for Persons with HIV* 43**
Wayne Smith Wayne Smith, Ph.D.
Deputy Director, Finance Systems and Quality Group,
Center for Medicaid and State Operations, CMS

HIV Care Research and Administrative Data Linkages 47
Lisa M. Lee, Ph.D.
Epidemiologist, Centers for Disease Control and Prevention

Improving Program Evaluation

***Cultural Competency in HIV Program Evaluation* 53**
Felipe G. Castro, M.S.W., Ph.D. and Hector Balcazar, Ph.D.,
=Arizona State University

***Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations* 61**
Robert Fullilove, Ed.D
Associate Dean for Community and Minority Affairs,
Columbia University

Summary of Individual Workgroup Discussions

Group One: AIDS Treatment Issues, Data Sources and Linkages for Treatment Research 67

***Group Two: Developing a Prevention Research Agenda* 69**

***Group Three: Injection Drug Use and Youth* 70**

***Overall Themes and Critical Issues* 72**



Introduction to The Conference Proceedings

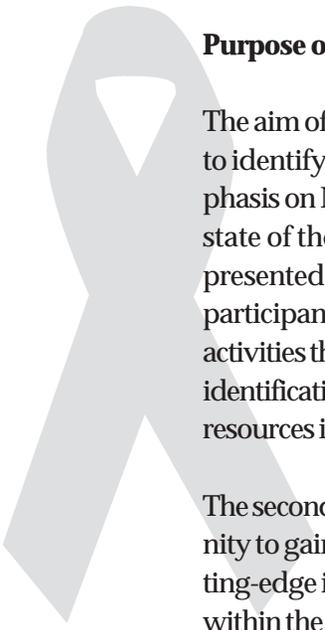
Twenty years into the AIDS epidemic, AIDS-related mortality is declining, but according to the Centers for Disease Control and Prevention (CDC), there is a continuation of new infections among the U.S. population. Based on the latest data, the director of the CDC's National Center for HIV, STD and TB Prevention indicates that the era of dramatic declines in AIDS cases and deaths experienced in the mid-1990s is now over. General concern is expressed by health officials and AIDS researchers as the plateau in reported cases and deaths in recent years yields to new findings that show higher rates of risky behavior—especially among certain populations. The CDC estimates that more than half the new infections are accounted for by low-income African-Americans. Although the overall health of the U. S. population has improved, including reduced numbers of HIV/AIDS cases reported among the White population, substantial disparities are observed among ethnic and racial groups, specifically African-American and Latinos, who represent approximately 65% of new cases. Escalating proportions of the newly-infected also include women and young gay men. Increasingly, questions are raised by federal and state government about how to address the causes that lead to increased infection rates among high risk populations (e.g., I.V. drug users, women, ethnic and minority groups). Continual steps must be taken to improve the scientific knowledge-base that in turn supports program efforts, aids in resource allocation determinations, and guides future program evaluations.

Many more persons today are living with HIV/AIDS than ever before, but additional resources are needed for prevention and treatment programs. States are faced with the tremendous task of improving the level of access to care for individuals with HIV/AIDS, as well as ensuring the provision of quality services for treatment. New research and program activities are critical in understanding how to improve the numbers of those in high risk populations who access testing and treatment facilities. Given the continual rise in infection rates, more exploration on prevention-focused programs; improved testing activities among those at most risk; and enhanced access, quality of care, and service delivery are essential. Information generated through such activities will aid states in making informed decisions about resource allocation, system accountability, and determining program effectiveness as they invest in AIDS services and programs. The basis of information for these activities is a broad but well defined research agenda that can help to answer questions about the population's behavior, care accessing, and system's effectiveness as increasing investments are made. Such exploration is critical for informing decision makers and providers of care as they continue to address challenges in AIDS prevention, care, and treatment.

With these challenges in mind, the Division of AIDS Prevention and Control contracted with Rutgers Center for State Health Policy (CSHP) to sponsor a research conference, aimed at providing a forum to exchange ideas, research experience, and develop suggestions for future program activities. Keen interest was expressed by State conference planning committee members in stimulating discussions and building relationships across disciplines, institutions and geographic locations to create new partnerships, influence practice and expand the existing research base.



Introduction to the Conference Proceedings *Continued*



Purpose of the Conference

The aim of the Research Conference on HIV/AIDS Prevention, Care and Treatment in New Jersey was to identify and present ongoing research activities on HIV/AIDS in the tri-state area with specific emphasis on New Jersey-based initiatives. Conference attendees were provided with information on the state of the epidemic in the country, the status of care and treatment services in general, and were presented with specific research activities taking place in New Jersey. Through a discussion process, participants were asked to make recommendations to state representatives about additional research activities that could prove helpful in the development of program improvement models, could aid in the identification of uniform standards for quality and outcome measures, and better promote utilization of resources in appropriate and effective evidenced-based interventions.

The second aim of the conference was to provide participants from a variety of settings with an opportunity to gain additional knowledge in prevention, care and treatment research activities, as well as cutting-edge issues and challenges. The focus of the conference was on research activities and experiences within the state of New Jersey. It is hoped that by sharing information across organizations and groups, both clinicians and researchers will work together more closely to address evaluative and programmatic shortcomings. Ultimately, research is essential in understanding behavior and all aspects of care and treatment. It is helpful in assuring quality of care, guiding program development, planning, priority-setting, resource allocation, and measuring outcomes. Finally, it provides the baseline by which to measure, and if applied, can continually influence future programs, demonstrations and directives, and enable the enactment of tremendous programmatic strides over time.

Organization of the Report

This report serves as the proceedings of the Research Conference on HIV/AIDS Prevention, Care and Treatment in New Jersey, June 14 and 15, 2001. The New Jersey Division of AIDS Prevention and Control within the Department of Health and Senior Services and the Rutgers Center for State Health Policy hope that the information provided in this report will be used by researchers to improve the focus of new and existing research agendas in the care, prevention, and treatment for persons with HIV/AIDS. The next section provides an overview of care, treatment, and current research in New Jersey. Subsequent sections contain summaries of the presentations made by conference speakers, as well as synopses of the workgroup discussions that took place at the conference in the following areas: AIDS Treatment Issues, Data Sources and Linkages for Treatment Research, Developing a Prevention Research Agenda, and Injection Drug Use and Youth.

To assist in summarizing the activities of the conference, workgroup participants selected a group leader to present challenges and recommendations they discussed within their topic area to the larger meeting group. After the individual session presentations took place, a discussion was held among all conference participants. In particular, the discussion identified issues and challenges that influence prevention, care and treatment programs within the state and the impact on service programs and clients. The report concludes with themes, issues and recommendations presented by the workgroups and subsequently prioritized by the larger body of conference participants.

New Challenges For HIV Prevention Research

Overview of the Epidemic — National Data

Summarized from the presentation made by Tanya Sharpe, Ph.D.

Epidemic Intelligence Service Officer, Centers for Disease Control and Prevention

In reviewing data from 1983, 1985, and 1999, it becomes apparent that the spread of HIV in the US has continued and clustered along the western border, the eastern seaboard, and in the southern portion of the country where the largest number of cases are observed*. Since 1981, over 730,000 cases of AIDS have been reported to the Centers for Disease Control and Prevention (CDC). At the beginning of the epidemic, 6% of all AIDS cases among adults and adolescents were among women; however in 1999, 23% of the reported cases were among women. The total number of cases reported each year is decreasing, after a large increase in 1993, when the case definition was expanded to include persons at an earlier stage of the disease.

Fifty-nine percent of the adults and 58% of children with AIDS have died. The annual number of deaths among persons with AIDS has decreased, although AIDS remains one of the leading causes of death among persons between the ages of 25 and 44. (The decreases in death partly reflect the leveling of AIDS opportunistic illness incidents, and improved survival among persons with AIDS due to advances in medical care, including antiretroviral treatments, introduced in 1996, that delay disease progression.) Trends in the incidents of AIDS must be viewed in light of changes in the history of the epidemic. The expansion of the case definition in 1993 created a large increase in the number of reported cases, requiring statistical adjustments to properly interpret trends in the AIDS incidence data during the 1990s. Trends in new infections are estimated to be stable at about 40,000 new cases per year.

Table 1: AIDS Cases and Deaths Reported through 1999, United States

	Cases	Deaths
Adult/Adolescent	724,656	425,357
Children	8,718	5,084
Total	733,374	430,441

Annual AIDS rates have dropped slightly in both New Jersey and New York. Connecticut has shown a slight increase in the number of AIDS patients per 100,000 from 18.7 to 19.7. The rate nationally is 15.7 per 100,000. However, the rates for the Tri-State area are slightly higher due to the larger number of injection drug users and their partners. Since 1981, 83% of AIDS cases were among men, and 17% among women. One percent of cases has been reported in children under 13 years of age. Forty five



Overview of the Epidemic - National Data *Continued*

percent of men and 43 percent of women were 30 - 39 years of age at diagnosis. Sixteen percent of men and 21% of women were in their 20s, and 27% of men and 22% of women were in their 40s. Overall, a slightly larger proportion of adolescent cases have been reported in women than men, 1% versus 0.3%. In 1999, 263 cases were reported among children under 13 years of age, and 312 cases were reported among adolescents 13 - 19.

The estimated number of persons living with AIDS has increased, from approximately 174,000 in 1993 to approximately 297,000 in 1998. The proportional distribution by race/ethnicity among people living with AIDS has changed since 1993. In 1998, 39% of persons living with AIDS were white, and 40% were black, compared with 46% white and 35% black in 1993. Small changes were seen in the proportions of other racial and ethnic groups. Data derived from a recent paper on survival after AIDS diagnosis demonstrates a pattern of improvement in survival after AIDS diagnosis among all ethnic groups after 1993. These improvements were probably due to advanced HIV therapies, and the increasing proportion of persons receiving these therapies. The proportional distribution of AIDS cases among racial and ethnic groups has shifted since the beginning of the epidemic. The proportion of cases among whites has decreased over time, while it has increased among blacks and Hispanics. As of 1996, a greater proportion of cases were reported among blacks than among whites. The proportion of cases reported among Asians, Pacific Islanders, American Indians and Alaska Natives has remained relatively constant at approximately 1% of all cases. In 1999, 32% of reported AIDS cases were among whites, 47% were among blacks, 19% among Hispanics, 1% among Asian and Pacific Islanders, and less than 1% among American Indians and Alaska Natives. The proportion of AIDS cases among men who have sex with men has decreased over time, from nearly 65% of cases diagnosed in 1985, to approximately 40% of cases diagnosed since 1998. The proportion of AIDS cases among injection drug users increased between 1985 and 1994, and has remained stable, accounting for approximately 25 to 29% of recently diagnosed cases. Of cases diagnosed in the first half of 1999, nearly 25% were attributed to heterosexual contact. The remaining 2% of cases included those attributed to hemophilia, the receipt of blood or blood products, and those without identified risk. AIDS cases are reported to the CDC with risk exposure information

Table 2: Annual AIDS Rates per 100,000 Population in the Tri-State Area

	July '98 - June '99		July '99 - June '00	
	Number	Rate	Number	Rate
Connecticut	612	18.7	648	19.7
New Jersey	2,048	25.3	1,925	23.6
New York	7,649	42.1	7,174	39.4
National	46,775	17.0	43,517	15.7

Overview of the Epidemic - National Data *Continued*

available at the time of the report. However, in many cases, the risk exposure is not yet identified, and becomes available after further epidemiologic follow-up.

Based on historical patterns of risk, distribution and reclassification, we can estimate the risk exposure for cases initially reported without risk information. This can only be done reliably by allowing for at least a six-month lag. When reviewing data allowing for that lag, we find that in cases reported from July of 1998 through June of 1999, approximately half of all adult and adolescent men with AIDS reported sex with men as a risk exposure. Another quarter reported being injection drug users. An estimated 13% of male cases are attributed to heterosexual contact. The other risk exposures account for the remaining 7% of cases. When adjusting for delays in reporting and proportional redistribution of cases initially reported without risk exposure information, the distribution of cases is more adequately depicted. Over one third of AIDS cases in adult/adolescent women diagnosed from July 1998 through June of 1999 were attributed to injection drug use. The majority of cases, 62%, were attributed to heterosexual contact and the other categories account for the remaining cases.

Because of advances in treatment of HIV disease, AIDS data are no longer adequate for describing the epidemic. The CDC is in the process of developing a national HIV reporting system that we hope will provide accurate and complete data on HIV, as accurate as the current AIDS system. As of March of 2000, 35 states conduct confidential, name-based HIV case surveillance. Two states, Connecticut and Oregon, conduct HIV case surveillance for pediatric cases. Because of the effects of antiretroviral treatment on AIDS incidents in recent years, HIV surveillance is important to help monitor the more current trends in HIV infection. Currently, several states are implementing non-name-based HIV surveillance systems, and other states are in the process of considering different HIV reporting systems. HIV data are important to collect, analyze, interpret and disseminate, in order to develop and enhance HIV prevention activities.

In 1999, 263 cases of AIDS were reported among children less than 13 years of age, a decrease from 382 in 1998. After follow-up for risk exposure, nearly all of the recent AIDS cases reported in children are found to be acquired through mother-to-child, or perinatal transmission. Perinatal transmission has declined steadily since 1994. Reasons for the decrease in pediatric AIDS include prevention of perinatal transmission through increasing use of antiretroviral therapies, improvements in the clinical management in women and children, and decreases in the number of HIV injected women giving birth. Surveillance data and studies suggest that the substantial and sustained decline in perinatally acquired AIDS can be attributed to: successful implementation of U.S. public health service guidelines for universal counseling and voluntary HIV testing of pregnant women, and the use of zidovudine (ZDV) by pregnant women and drug administration to newborns. The prevention successes in perinatal HIV transmission are examples of the direct use of surveillance data to measure the effect of prevention as national data illustrates a dramatic decrease in perinatal transmission. Children born to women diagnosed with HIV before delivery who received any ZDV, either perinatally, during delivery or after delivery, only -8% were infected, compared with 16% of those who did not receive the drug. The rate was 12% for those whose ZDV was unknown, suggesting that at least some children might have received ZDV.



Overview of the Epidemic - National Data *Continued*



Prevention successes in the 1980s and 1990s helped significantly reduce annual HIV infections from a peak of 150,000 per year, to 40,000 per year, but making further reductions will require a major expansion in prevention. The CDC estimates that nearly 300,000 Americans who are HIV positive are unaware of their infection. The CDC encourages mobilization to increase the proportion of HIV infected individuals who know their status from the current 70% to 95%, by making anonymous and confidential HIV testing widely available in public and private healthcare settings. The CDC's goal for the next five years is to increase the proportion of HIV infected people who are linked to appropriate prevention, care and treatment service from the current rate of 50% to 80%. This will be accomplished through the linking of more than 800,000 to 900,000 HIV positive Americans to prevention and care services, testing and developing HIV prevention messages and campaigns, and by providing initiatives for research into behavioral interventions that work to reduce risk behavior. The five-year CDC goal is to decrease by 50% the number of individuals at risk for acquiring or transmitting HIV infection, by delivering targeted, sustained, and evidence-based HIV prevention interventions, targeting the following groups: communities of color, men who have sex with men, men who have sex with men with sexually transmitted diseases, youth, women, and injection drug users and their sex partners. These prevention strategies should be varied to reach all people of all socioeconomic groups. Specific prevention outreach strategies should be targeted toward indigent populations to improve knowledge about the risks of contracting HIV, modes of transmission and the importance of early testing since this group compared to others continues to display high rates of HIV positives. Poor people are not getting the message about the risks of contracting HIV. Public health professionals are charged with getting the message to all persons at risk.

The successes to date are good news for people with HIV who now have longer and better lives, but the availability of treatments may lull people into believing that prevention activities aimed at thwarting the spread of HIV are no longer important. Complacency about preventing AIDS is a new dimension of complexity for program planners and individuals at risk. Access to care is also problematic for some. The poor, the homeless, and people who use street drugs may have difficulty getting tested and receiving care. Others may have challenges adhering to HIV drug regimens due to the side effects and the costs of medication. Adherence to HIV medications may also be problematic for people who use drugs. In a study conducted examining black women who use crack cocaine and adherence to HIV medications, it was found that those who use drugs, especially those who use crack cocaine, were less likely to take their medicines exactly as prescribed. This highlights the complex nature of providing services to some HIV infected individuals. A notable number of HIV infected persons are substance abusers.

HIV reporting in all states will help to better characterize the epidemic. The changing demographics of the epidemic may reflex testing and reporting behavior. For example, people with private doctors or abundant resources may not be captured by current surveillance systems. Strategies for better reporting should include methods for encouraging more healthcare professionals to participate in HIV reporting. Research should be conducted on barriers to prevention among minorities. This is an area that requires intense energy and focus in academia and other research institutions. Research also needs to be conducted on the barriers to testing in high-risk communities. Since people are living longer with HIV, and the disease is shifting toward being considered both infectious and chronic, more studies should be conducted among people living longer with HIV and AIDS. These studies could shed light on the progression of the disease over time, and help us understand the problems of living with the disease, and the long-term effects of HIV medications.

The National Perspective on Treatment Research

Summarized from the presentation made by Katherine Marconi, Ph.D., M.S., Director Office of Science and Epidemiology, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)

The mission of the Health Resources and Services Administration (HRSA) is to assure the delivery of primary health care and supportive services to individuals throughout the United States who are uninsured and underinsured. In recent years this responsibility has grown in both scope and complexity as the number of individuals who are uninsured has risen to over 30 million and the management of the diseases that are being diagnosed has become more complex. The HIV/AIDS Bureau in HRSA is a relatively new Bureau that addresses a fairly new disease. Our clients frequently come from very underserved and marginalized populations, and they may have other more pressing co-morbidities such as substance abuse and mental illness. Because of these challenges, the Bureau's approach to treatment research is really an approach to applied research on the delivery of quality HIV care and support. The Bureau, through its Ryan White CARE Act (CARE Act) grantees—such as the State of New Jersey, does not undertake clinical trials. Rather we look at how to adapt and make use of the best in clinical practice for our populations. Care and support add another dimension to the medical treatment in our programs. There are many support services such as case management, transportation, and emergency assistance that are provided through the CARE Act. For these reasons the following presentation focuses on how program evaluation and health services research may be used to improve HIV care and treatment, not just treatment.

The CARE Act was reauthorized by Congress last year. The reauthorization themes form a national agenda for applied research. The themes center on equity—equity in accessing HIV care and in assuring quality care. They include bringing individuals not in regular medical care into care; improved quality management of care; capacity building of services in underserved communities, especially racial and ethnic communities; resource targeting to those communities; coordination and linkage among publicly funded programs. These themes can be further developed into research questions that each grantee should be addressing to improve HIV care within their state, city, or market area. Such themes and questions include:

- To what extent are CARE Act grantees and Titles I and II providers identifying HIV infected populations who are not in primary health care and not accessing available services? Associated Study Question: To what extent are grantees identifying HIV-infected populations who are not remaining in primary health care and the reasons for this lack of continued service utilization?
- Are grantees determining the specific reasons why individuals are not in care and removing barriers to their care? Associated Study Question: What are grantees/providers doing to enroll and retain identified underserved populations in primary health care?



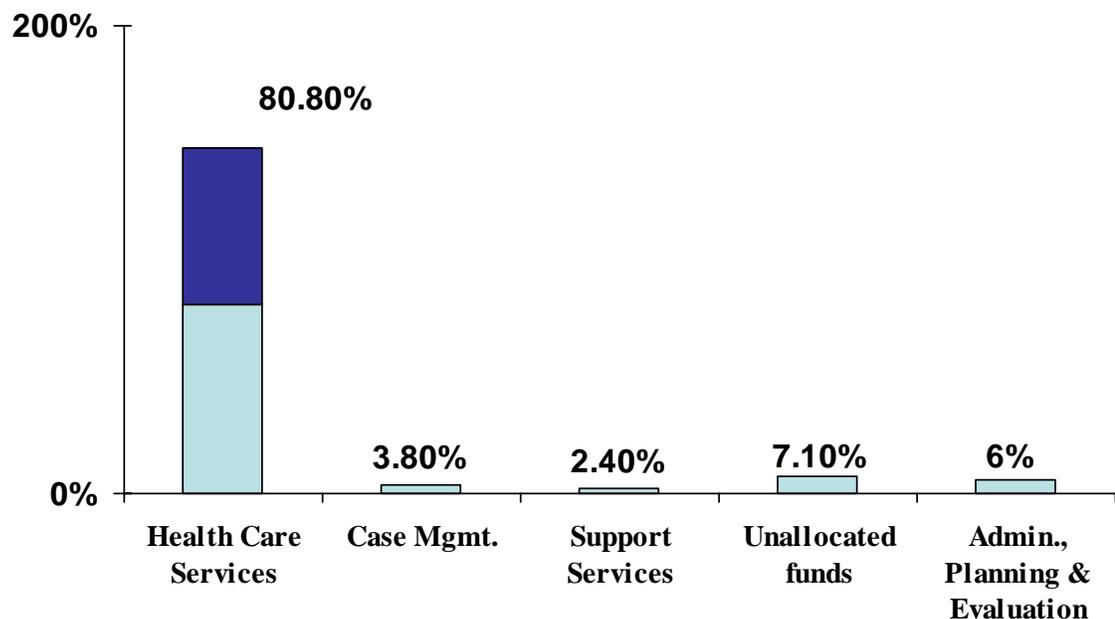
The National Perspective on Treatment Research *Continued*



- Have CARE Act grantees identified the most effective combinations or models of integrated services that improve the use of primary health care, taking into account the characteristics of local health care delivery systems and affected populations?
- To what extent are CARE Act grantees/providers providing quality care to clients as defined by Public Health Service and other care standards? Associated Study Question: Is this care having optimal effects on morbidity and mortality, and is it improving health-related quality of life?
- To what extent are CARE Act grantees adapting their service priorities and allocations to a changing and sometimes chaotic health delivery and reimbursement environment? Associated Study Question: Within Title II states and Title I Eligible Metropolitan Areas (EMAs) can CARE Act funding be most efficiently combined with Medicaid funding to assure a continuum of care.

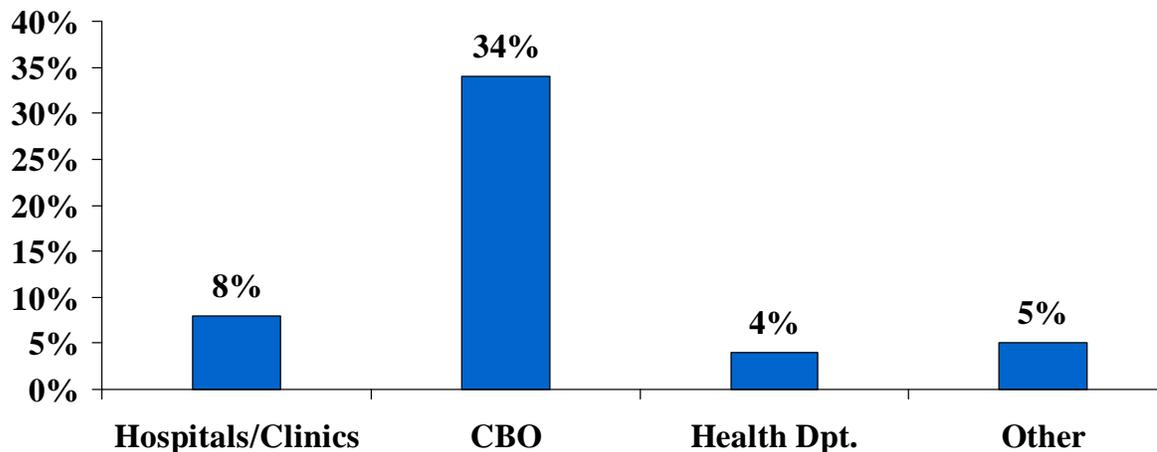
Underlying the reauthorization themes and research questions is the priority of targeting funding to the racial and ethnic minorities who now are bearing the greatest burden of this disease. The Minority AIDS Initiative has provided HRSA with \$12 million in FY 1999, \$74.1 million in FY 2000, and \$110.2 million in FY 2001 to increase the use of HIV care by individuals from African American, Hispanic, Asian-Pacific Islander and other minority populations. The funds are allocated by formula to Titles I, II, III, and IV of the CARE Act and the AETC program. Several reauthorization themes come from the Minority AIDS Initiative such as: 1) the authorization of HRSA to make direct, targeted grants of up \$150,000 for capacity building; (2) the ability of local Title I planning councils, which make funding decisions for

Figure 1: 1999 New Jersey Title II Grantee Services Allocations



The National Perspective on Treatment Research *Continued*

**Figure 2: 1999 New Jersey Title II CARE Act Clients
Types of Organizations Providing Services**

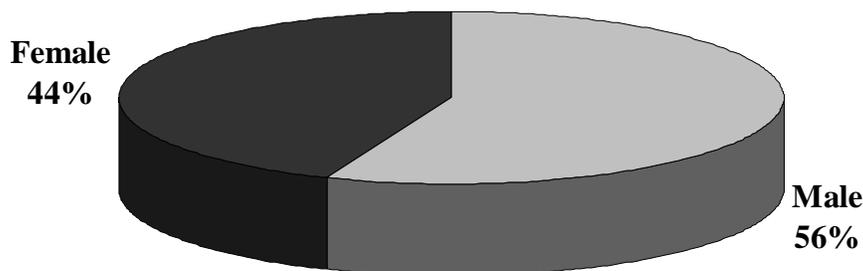


metropolitan areas, to put money into infrastructure and capacity building; and (3) a mandate for CARE Act planning bodies to conduct detailed assessments of HIV-infected persons not in care and support mechanisms needed to get them into regular, high-quality medical care.

State Level Care and Treatment Research

There are a number of ways in which states like New Jersey can initiate care and treatment research that addresses this national perspective. Some of the methods are relatively simple, such as geo-mapping. We know from annual program reporting who our CARE Act clients are. Is it possible to gather zip codes of

**Figure 3: 1999 New Jersey Title II CARE Act Clients
By Gender**



The National Perspective on Treatment Research *Continued*

Figure 4: 1999 New Jersey Title II CARE Act Clients

By Race/Ethnicity

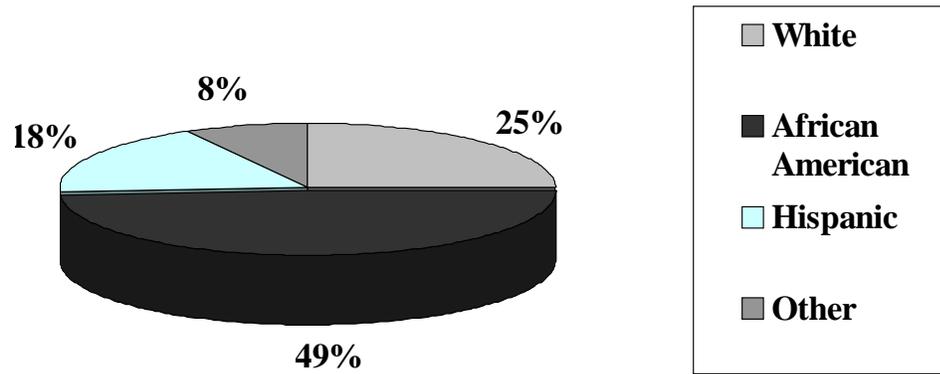
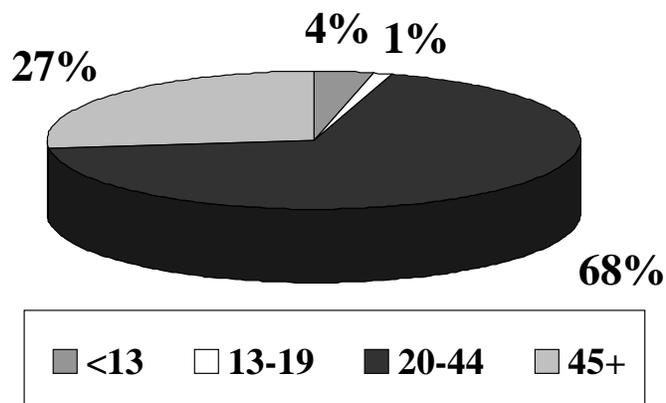


Figure 5: 1999 New Jersey Title II CARE Act Clients

By Age



The National Perspective on Treatment Research *Continued*

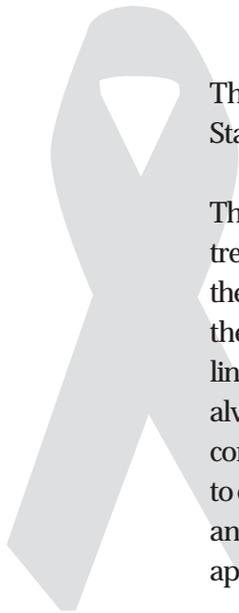
these individual's residence and map where they live compared to state HIV reporting? Is this information useful in Title I Planning Council and Title II Consortia planning? Another possibility is to map provider locations by service type and HIV incidence. For example, to what extent are providers of case management conveniently located for newly infected individuals? Also, are existing service allocations appropriate or should there be greater allocations to case management and support services to improve the quality of existing care programs?

Another possibility is to map provider locations by service type and HIV incidence. For example, to what extent are providers of case management conveniently located for newly infected individuals. There are many other data sets, such as the Centers for Disease Control and Prevention's Adult Spectrum of Disease (ASD) that may provide information for geo-mapping. Information from medical records, such as the ASD, also offer an opportunity to assess quality of care. Nationally, HRSA has partnered with the Institute for HealthCare Improvement (IHI) to increase the quality of HIV care delivery among its grantees. Currently IHI is coordinating a Breakthrough Series Collaborative on Improving Care for People Infected with HIV. About 80 CARE Act providers participate. The collaborative joins data collection and analysis with quality improvement through a plan, study, and act cycle. It takes about a year to complete during which participants monitor access to and retention in care, viral load and CD4 counts, percent patients on HAART and self-management and adherence support. It is a model for future program evaluation because of its shared emphasis on data and action.

Beyond good descriptions of the problem, we need to move to more rigorous analytical studies of our challenges in improving HIV care. These studies should be both qualitative and quantitative in nature. For a conference that HRSA convened in 2001 we reviewed the literature on HIV care and treatment that addressed underserved populations. Some of the gaps in our approaches to research were identified including: evaluation and research studies should focus on questions that are relevant to populations disproportionately affected by the HIV/AIDS epidemic (e.g., African Americans, youth). Additionally priority should be given to the training of researchers from these groups, the development of rapid response methods to quickly conduct qualitative research, and multiple levels of analysis including individuals, clinicians, organizations, service delivery systems, and the cultural, economic and political environments.

The conference proposed that specific analytical studies might address:

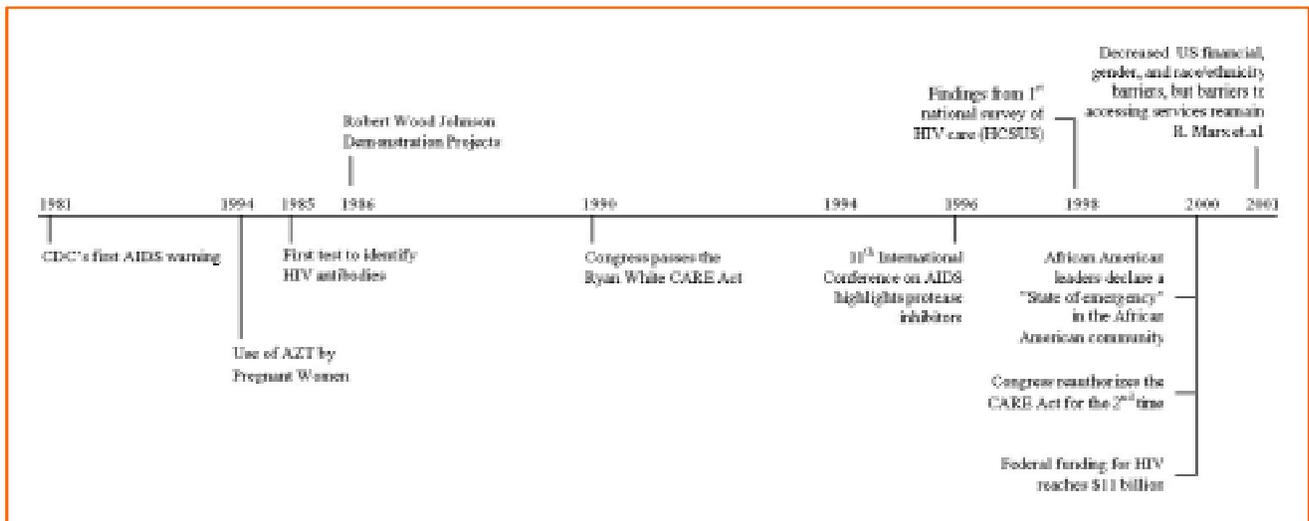
- The kinds of interdisciplinary teams that are needed to effectively manage HIV infection and co-existing chronic illnesses. How should they be funded?
- The patterns of service integration that are associated with better clinical outcomes. What performance measures are appropriate?
- Research on strategies to overcome very complex historical biases against African Americans and other racial, ethnic and gender groups in health care.



There has been a great deal written about the 20th anniversary of the AIDS epidemic in the United States. Frequently this history is pictured as an AIDS timeline as shown in Figure 6.

The visualization of this timeline provides instruction on how we have approached HIV/AIDS care and treatment research and the future directions that we need to take. First, change is constant throughout the epidemic—change in the people who are infected, the co-morbidities associated with this disease, and the treatments available. Research must address this constant change. Secondly, while the timeline is linear, the change is not. If re-drawing this timeline, perhaps a fractal would be more appropriate. Fractals always are in a state of flux and it is difficult to chart where their boundaries end or begin. As New Jersey considers what its research agenda is for HIV care and treatment, it also must be flexible and responsive to change. Research results must be useful to policy makers, program administrators, service providers, and to the communities impacted with this disease. It is critical to assuring the wise allocation and appropriate use of our limited resources for HIV/AIDS care.

Figure 6: AIDS Timeline



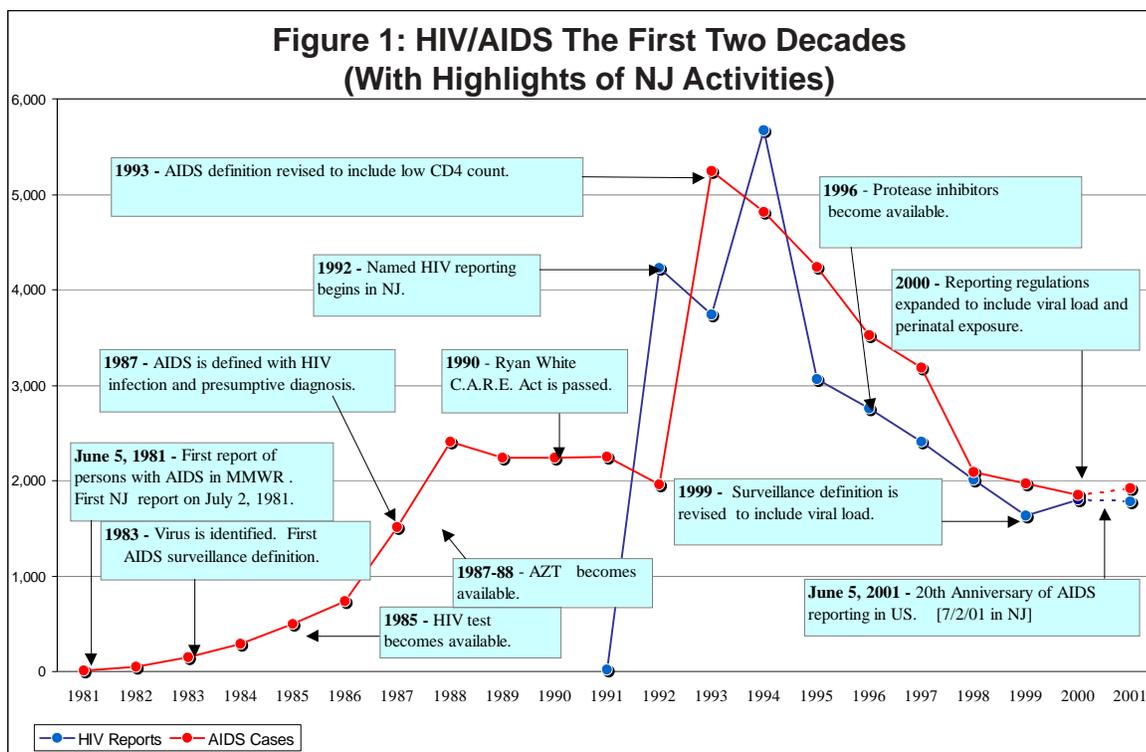
Overview of HIV/AIDS Care and Treatment Background and Research in New Jersey

Summarized from the presentation made by Sam Costa, M.S.

Director, Division of AIDS Prevention and Control, New Jersey Department of Health and Senior Services

The Surveillance Unit within the division of HIV Prevention and Control began the collection of information on HIV cases and reports in the State of New Jersey at the end of 1991. Surveillance data collected consists of provider submitted data, lab reports, CD4 counts, viral loads, and HIV test results. In the early years of the epidemic (from about 1987 to 1991), the State Department of Health noted fewer than 2,000 cumulative AIDS reports. Today, there are 2,000 to 3,000 reports per year of people with HIV. Over the years, reporting definitions have been expanded to include presumptive diagnoses and HIV results, immunological results, CD4 counts, the use of protease inhibitors, and viral load results. (See Figure 1) Since 1987, the state has had over 57,000 persons from New Jersey reported with HIV/AIDS. Sixty-nine percent were male, 31% female, over half have been African-American, 25% White, and 17% Hispanic. There have been over 28,000 deaths among persons reported with HIV/AIDS in this state.

Since 1983, the largest group in New Jersey reported with HIV are injecting drug users. This is the single largest mode of transmission in New Jersey although not the only mode of transmission. For single males ages 20 to 29 living with HIV, there are more men having sex with men and contracting the disease

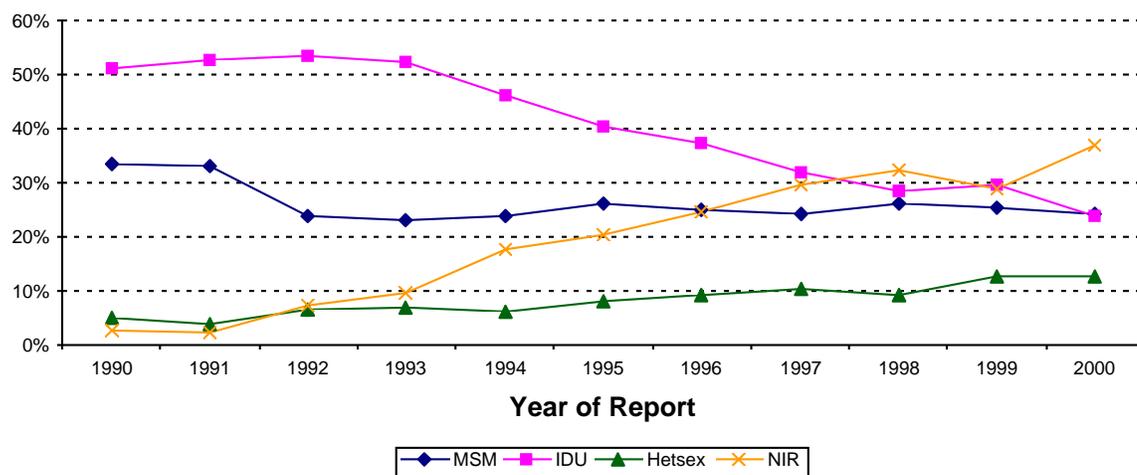


Overview of HIV/AIDS Care and Treatment Background and Research in New Jersey *Continued*

as opposed to transmission as a result of injection drug use. When looking at adolescents and young adults, ages 13 to 24, there are more females (52%) than males within this age group who are HIV positive. New Jersey holds the dubious distinction of proportionally having more women who are HIV positive than other states.

The number of persons living with HIV in New Jersey continues to grow. In the last ten years, we find that approximately 67% of the persons reported with HIV are males (down from about 75% in the early years of the epidemic). (See Figure 2) In looking at race/ethnicity, over half of the persons reported in the last decade are African-American and reported Hispanics have increased to about 20% while the proportion of Whites has declined from 30% to 20%. (See Figure 3) In assessing the trends among male

Figure 2: Trends in HIV/AIDS Report Incidence: Percent Distribution of Male Adult/Adolescents, by mode of Transmission and Year of Report, 1990-2000



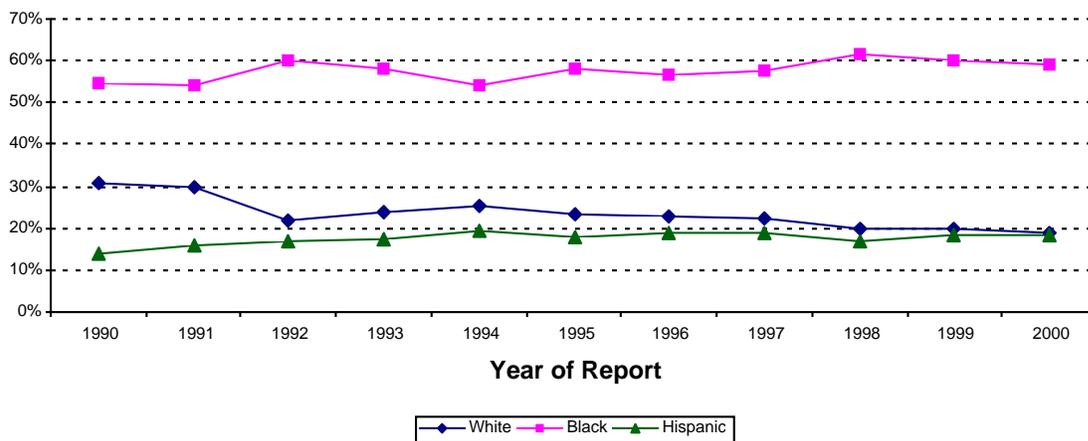
adults and adolescents within a twenty year period, two things become apparent: the injecting drug use proportion is going down and the unreported cases are going up (and within this, the heterosexual cases are going up). When comparing geographic areas within the state where large numbers of people are infected, it was found that the largest numbers of people infected are in Newark.

When reviewing perinatal surveillance data, we find that there has been a reduction in transmission rates from mother to child and a definite reduction in the percent of infants infected. Over the last decade, the state of New Jersey has experienced a reduction in the numbers of HIV exposed infants (approximately 300 cases which is half of what was reported in the early 90s).

Overview of HIV/AIDS Care and Treatment Background and Research in New Jersey *Continued*

In summary, there is clearly a need for continued surveillance activities but beyond that, more effort to move suspected positives to testing and treatment. Additional research needs to occur to assess what are the effective programs that facilitate more of the “hard-to-reach” population into testing and treatment, keep them participating over time and practicing prevention techniques to minimize further exposure and spreading infection.

Figure 3: Trends in HIV/AIDS Report Incidence: Percent Distribution of Persons by Race/Ethnicity and Year of Report, 1990-2000



New Challenges For HIV Prevention Research

Prevention Through Peer Advocacy

**Summarized from the presentation made by Robert L. Johnson, M.D., F.A.A.P.
Professor and Vice Chair of Pediatrics, Professor of Psychiatry, Director of the Division of Adolescent and Young Adult Medicine, University of Medicine and Dentistry – New Jersey Medical School**

Although there are no direct measures of the rates of HIV disease in the sexually active adolescent population, the causal and potentiating relationships between unprotected sexual intercourse and HIV transmission makes rates of sexual activity, teen pregnancy, STD's, substance use and delinquency good surrogate measures of the local spread of adolescent HIV disease.¹ Given this assumption the prevalence of STD's and pregnancy in the adolescent population suggest that there is a significant reservoir of HIV infection. However, because these young people are asymptomatic they are very unlikely to become aware of their HIV infection until they become symptomatic during their adulthood. This fact has taken on new urgency now that advances in science and medical care have enabled individuals "living with HIV/AIDS" to live longer, healthier lives. New therapies are now available that prevent and/or effectively control opportunistic infections and slow the progression from HIV infection to AIDS. These improved outcomes are dependent on early diagnosis and early involvement in a continuum of HIV/AIDS care.² However early diagnosis has proven challenging because of the difficulties encountered in engaging populations of high-risk teens in effective HIV counseling and testing.

Barriers to HIV counseling and testing among adolescents have been well documented in the literature^{3,4,5}. Most often these impediments are related to the following issues:

- Lack of knowledge about HIV disease,
- Lack of knowledge about the consequential link between a given behavior and HIV disease,
- Adolescent omnipotence,
- The availability of HIV counseling and testing,
- Fear of the testing process,
- Insurance issues / cost,
- Consent and confidentiality.

A number of innovative programs have been developed to reach adolescents utilizing peer-centered street based outreach for "adolescent specific" HIV counseling and education^{6,7}. However few of these programs have offered street based HIV testing.

In our community we have responded to the urgency to identify HIV infected youth with a two-phased program of street based peer outreach and community based HIV counseling and testing. The program has been designed to target high risk adolescents with a set of interventions intended to remove the barriers listed above.



Prevention Through Peer Advocacy



Counseling and Testing Program

The first phase: **Peer Outreach Workers Educating Risk-takers (POWER)**, is an outreach and risk reduction program for adolescents and young adults at-risk of HIV/AIDS. In contrast to approaches that have targeted institutional adolescent populations (schools, youth groups), POWER seeks out populations of adolescents not found in traditional settings - street youth, gay and bisexual youth and teens involved in commercial sex work (prostitution) and drug use/abuse/sales/distribution. The POWER Team interfaces directly with these high-risk adolescents through brief non-threatening contacts initiated within their natural peer environment. During these interfaces the POWER Team delivers messages that are developmentally, culturally, ethnically, gender and environmentally sensitive to the unique proclivities of the various adolescent populations.

The Peer Outreach Workers are recruited, trained and supervised by the Peer Outreach Coordinator. The coordinator is selected for his/her experience and training in HIV risk reduction and youth development. In the recruitment of the Peer Outreach Workers we have made a special effort to identify youth who are familiar with the Newark street environments and the high risk behaviors which place youth at risk of HIV infection.

Training occurs over 13 weeks in 3 weekly one hour sessions that address the following curricular content:

- Counseling, Focus Group Technique, Role Playing, Data Collection
- HIV Infection/transmission
- HIV Risk Reduction
- Adolescent Growth and Development
- Adolescent Health Promotion and Health Behaviors
- Adolescent Sexuality and STD's
- Adolescent Drug and Alcohol Use and Abuse
- Depression, Suicide, Violence
- Adolescent Nutrition

Following training the regular supervision of the POWER Team members includes weekly "booster" training sessions to facilitate the transfer of HIV/AIDS outreach technology. Under the direction of the Peer Outreach Coordinator the POWER Team develops scripted outreach messages and decides the contents (types of condoms, brochures, etc.) of HIV/AIDS outreach kits that the team distributes during community outreach contacts.

The team participates in weekly supervisory sessions in which their activities are monitored and evaluated to ensure the implementation and efficacy of the program's goals and objectives. These supervisory sessions are also used to modify the intervention in response to the reaction of the target population.

Outreach activities take place in the following settings:

Supervised Area Canvassing: each week the POWER Team canvasses and distributes outreach kits and messages in a specified area of our community. The choice of the community area is a team decision of the

Prevention Through Peer Advocacy

POWER Team members based on their survey of sites of youth congregation (SYC's). The team members work in pairs from a central display base and visit playgrounds, shopping districts (including malls), sporting events, social clubs etc. Each contact also includes an invitation to visit POWER House (the program's community based outreach center) to obtain additional information, condoms and counseling.

Ad Hoc Outreach: In addition to the weekly area canvassing each team member is required to make 10 outreach/risk-reduction contacts within their own peer group settings. In each contact the team member distributes an outreach kit, delivers a scripted outreach message and invites the "contactee" to visit POWERHouse.

Power House Open House: POWER's community based facility is open on a daily basis when the team is not involved in canvassing activities. Young people may visit the facility to obtain additional condoms and HIV related information.

During outreach in each venue the members of the POWER Team facilitate HIV testing in one of three sites associated with the program:

- Counseling and testing is immediately available on the STOP mobile testing van which works in conjunction with the team,
- Counseling and testing visits may be scheduled at DAYAM's medical clinic or at POWER House.

The second phase: STOP [Spend Time On Prevention], is a mobile HIV counseling and testing unit which is dedicated to the counseling and testing of adolescents and young adults. The van is staffed by three New Jersey State certified HIV counselors/phlebotomists who have been trained to appreciate and respond to the special counseling and case management issues which are presented by youth who seek HIV testing. Youth who come onto the van are counseled to determine and enhance their HIV knowledge and determine and reduce their participation in HIV risk behaviors. The staff also initiates case management procedures which are designed to establish the linkages and tracking procedures which will ensure that tested youth return for post-test counseling and that infected youth are appropriately engaged into treatment. Saliva samples are collected using Orasure kits and transmitted to state labs for Elisa/Western Blot testing. All services are free.

During 1997 the members of the POWER Team engaged 1,550 youth in one-to-one, on-the-street outreach, and tested 666 youth for HIV on the STOP van. During each street-based outreach session a member of the team was assigned to randomly approach youth who had been engaged in outreach. These young people were asked to assist in the evaluation of our program by completing a 15 item multiple choice survey to determine characteristics of the youth engaged through this type of outreach. One hundred and seventy five surveys were completed by recipients of outreach who were randomly approached by members of the team. The sample included 83 (47%) males and 92 (53%) females. All of the respondents were African American. The mean age for all respondents was 18.14 years (male 17.9



Prevention Through Peer Advocacy

years female 18.4 years). The majority of respondents (88% of the male and 85% of the female) reported that they were sexually active. Chi Square tests were used to evaluate the significance of our findings.

Analysis of the results revealed the following answers to the questions posed by our inquiry:

Question 1: Are the adolescents and young adults who are contacted in street outreach activity individuals who engage in high-risk sexual activities?

Although the male respondents were significantly more likely than the females to report that they currently always used condoms, condom use was common among both the male and female sexually active respondents (see Table 1).

Table 1: Frequency of Condom Use

	Always	Sometimes	Never
All Respondents	84 (50%)	64 (38%)	20 (12%)
Male	49 (61%)	28 (35%)	3 (4%)
Female	35 (40%)	36 (41%)	17 (19%)

p=.002

However when respondents were requested to report on the number of times they had engaged in unprotected sexual activity within the last year only 19% of the males and 17% of the females were able to say that they had never had unprotected sexual activity during the specified reporting period. Indeed 27% of males and 47% of females had 5 or more episodes of unprotected sexual activity within the past year (see Table 2).

Table 2: Frequency of Unprotected Sexual Activity

	Never	Less than 5	5 – 10	More than 10
All Respondents	30 (18%)	75 (45%)	30 (18%)	32 (19%)
Male	15 (19%)	43 (54%)	11 (14%)	10 (13%)
Female	15 (17%)	32 (36%)	19 (22%)	22 (25%)

P=0.052

65% of all respondents reported that they were involved in monogamous relationships. However this group bias against simultaneous multiple relationships was due entirely to the highly significant tendency for the female respondents to select this type of sexual relationship (see Table 3).

Prevention Through Peer Advocacy

Table 3: Monogamy

	Monogamous	Non-Monogamous
All Respondents	105 (65%)	56 (35%)
Male	39 (50%)	39 (50%)
Female	66 (80%)	17 (20%)

p=.001

Compounding the risk associated with non-monogamous relationships among the male respondents was the finding that 61% of the sexually active male respondents had more than 5 lifetime sexual partners (see Table 4).

Table 4: Number of Lifetime Sexual Partners

	None	1 – 5	More than 5
All Respondents	4 (2%)	103 (61%)	62 (37%)
Male	2 (3%)	29 (36%)	49 (61%)
Female	2 (2%)	74 (83%)	13 (15%)

P=0.001

Question 2. Do the adolescents engaged through street outreach have outcomes as a result of high-risk sexual behaviors that suggest they are at risk of the acquisition of an HIV infection?

The most salient outcomes that are indicative of the probability of risk behavior causing these types of adverse outcomes are STDs and pregnancy. Although the respondents indicated relatively high rates of protective sexual activity they also had very high rates of pregnancy and STDs. Fifty two percent (52%) of the female respondents had experienced at least one pregnancy and 39% of the males had fathered at least one pregnancy (see Table 5). The difference in pregnancy rates between the male and female respondents was not significant. Eighteen percent of the males and 6% of the female respondents reported that they had experienced at least one sexually transmitted infection. There was a significant difference by gender in this category.

Table 5: High Risk Outcomes

Males who have fathered a pregnancy	39%
Females who have experienced a pregnancy	52%
<i>p=.107</i>	
Males who have had an STD	18%
Females who have had an STD	6%
<i>p=0.015</i>	



Prevention Through Peer Advocacy

Among the male respondents there was a borderline significant difference in the probability of having fathered a pregnancy between those who had experienced and those who had not experienced a sexually transmitted infection (26% vs. 1% $p=0.079$). This difference was not significant among the female respondents.

Question 3. Is there an interaction between high-risk sexual behaviors and adverse sexual outcomes among the population of adolescents engaged through street outreach?

Those respondents who had experienced a sexually transmitted infection were not different from those who had not experienced an STD in any of the comparative measures of protected vs. unprotected sexual activity, monogamy, condom use or access to condoms (see Table 6).

Table 6: Monogamy, Access to Condoms and Condom Use Vs. STD History

	Males With History of STD	Males Without History of STD	Females With History of STD	Females Without History of STD
Monogamous Relationships	49%	50%	100%	79%
		$p=0.957$		$p=0.256$
Access To Condoms	86%	83%	100%	91%
		$p=0.809$		$p=0.496$
Consistent Condom Use	50%	62%	40%	40%
		$p=0.319$		$p=1.00$

However among female respondents there were significant differences in history of STD in terms of numbers of sexual partners in the last two years and discussions of safe sex with sexual partners. There were also significant differences in numbers of episodes of unprotected sexual activity (see Table 7). For

Table 7: Unprotected Sex Episodes, Safe Sex Discussions Vs. STD History

	Males With History of STD	Males Without History of STD	Females With History of STD	Females Without History of STD
More than 5 Episodes of Unprotected Sex	42%	30%	100%	52%
		$p=0.469$		$p=0.039$
Discuss Safe Sex with Partner	92%	79%	40%	88%
		$p=0.274$		$p=0.003$

Prevention Through Peer Advocacy

the group as a whole those who had a history of STD were significantly more likely to have had a greater number of sex partners in the last two years ($p=0.017$).

There were no significant differences in reported birth control use, access to condoms, consistent condom use and safe sex discussions with sexual partner between those who had experienced or fathered a pregnancy and those who had not experienced or fathered a pregnancy.

For the group as a whole those who had not experienced or fathered a pregnancy reported less frequent episodes of unprotected sex. However this difference was only significant among the female respondents (see Table 8). Both male and female respondents who had caused or experienced a pregnancy tended to have had more than 5 sexual partners in the last two years. However this difference was borderline significant among the male respondents and not significant among the female respondents.

Table 8: Number of Sexual Partners, Number of Episodes of Unprotected Sex vs. Pregnancy History

	Males Who Fathered a Pregnancy	Males Who Had Not Fathered a Pregnancy	Females Who Had Experienced a Pregnancy	Females Who Had Not Experienced a Pregnancy
More Than 5 Sexual Partners	71%	56% <i>p=0.087</i>	20%	9% <i>p=0.171</i>
More Than 5 Episodes of Unprotected Sexual Activity	39%	29% <i>p=0.370</i>	68%	41% <i>p=0.018</i>

Question 4. Are the adolescents engaged through street outreach personally concerned about HIV infection?

Sixty six percent (66%) of male and 53% of the female respondents thought that they could become HIV infected. The difference by gender was not statistically significant. Fifty nine percent (59%) male and 75% of the female respondents had been tested for HIV infection. This gender difference was significant ($p = 0.035$).



Prevention Through Peer Advocacy

Question 5. Is there an interaction between high-risk sexual behaviors/outcomes and concern about HIV infection among the population of adolescents engaged through street outreach.

Among the respondents questioned in this survey those who had experienced or fathered a pregnancy were significantly more likely to have had an HIV test than those who had not experienced or fathered a pregnancy. There were no other significant interactions between high-risk sexual behaviors/outcomes and HIV related protective behaviors (see Table 9).

Table 9: HIV Concern vs. History of STD, Pregnancy

	Male STD	Male No STD	Female STD	Female No STD	Male Pregnancy	Male No Pregnancy	Female Pregnancy	Female No Pregnancy
Ask HIV Status	69%	70% <i>p=0.928</i>	60%	79% <i>p=0.312</i>	73%	68% <i>p=0.634</i>	85%	71% <i>p=0.129</i>
Think Could Become HIV Infected	85%	61% <i>p=0.106</i>	60%	52% <i>p=0.725</i>	72%	63% <i>p=0.396</i>	50%	56% <i>p=0.574</i>
Had HIV Test	77%	57% <i>p=0.177</i>	80%	74% <i>p=0.779</i>	73%	49% <i>p=0.037</i>	87%	62% <i>p=0.007</i>

Question 6. Does personal concern about HIV infection among adolescents engaged through street outreach affect their involvement in high-risk behaviors?

Thinking that you could become HIV infected or having an HIV test did not affect the numbers of sexual partners that one has in a two-year period of time. Similarly thinking that you could become HIV infected or having an HIV test did not affect the numbers of episodes of unprotected sexual activity. However respondents who were in monogamous relationships were significantly more likely to feel that they could not become HIV infected. This difference was most highly significant among the female respondents. On the other hand monogamous and non-monogamous respondents were HIV tested at the same rate. Respondents who thought that they could become HIV infected and respondents who had been HIV tested tended to discuss safe sex with their partners at the same rate as respondents who do not think they could become HIV infected. All respondents who thought that they could become HIV infected and males who were HIV tested did not vary significantly in their condom use behaviors with respondents who did not think that they could become HIV infected. However there was a significantly strong tendency for females who were not HIV tested to be consistent condom users.

Prevention Through Peer Advocacy

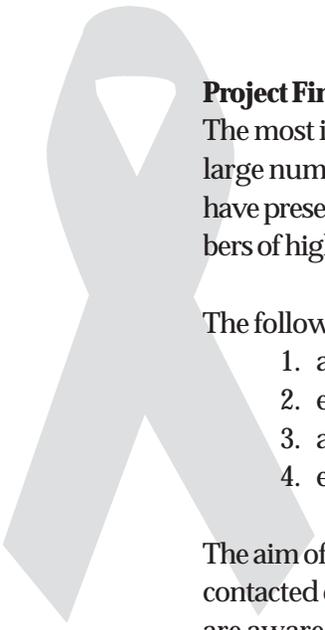
There were no significant interactions between thinking that you could become HIV infected and asking about your partner's HIV status however female respondents who had had an HIV test strongly tend to ask their partners about their HIV status more than respondents who had not had an HIV test. Respondents who thought that they could become HIV infected and those who had been HIV tested had a frequency of unprotected sex that was not significantly different from the unprotected sex practices of those who did not think that they could become HIV infected (see Table 10).

Table 10: Personal Concern About HIV Infection vs. HIV Risk Behaviors

	Males Think Could Become HIV +	Males Think Could Not Become HIV+	Females Think Could Become HIV+	Females Think Could Not Become HIV+	Males HIV Tested	Males Not HIV Tested	Females HIV Tested	Females Not HIV Tested
More Than 5 Sexual Partners	65%	60% <i>p=0.663</i>	16%	15% <i>p=0.948</i>	68%	44% <i>p=0.404</i>	18%	5% <i>p=0.128</i>
Monogamous Relationships	46%	60% <i>p=0.251</i>	67%	92% <i>p=0.009</i>	48%	53% <i>p=0.636</i>	79%	80% <i>p=0.926</i>
Discuss Safe Sex with Partner	83%	80% <i>p=0.755</i>	89%	80% <i>p=0.256</i>	76%	87% <i>p=0.212</i>	86%	82% <i>p=0.169</i>
Consistent Condom Use	65%	56% <i>p=0.754</i>	32%	48% <i>p=0.340</i>	61%	60% <i>p=0.906</i>	32%	59% <i>p=0.026</i>
Ask Partners HIV Status	72%	75% <i>p=0.811</i>	73%	85% <i>p=0.189</i>	72%	67% <i>p=0.619</i>	83%	64% <i>p=0.052</i>
More Than 5 Episodes of Unprotected Sexual Activity	38%	25% <i>p=0.333</i>	53%	45% <i>p=0.572</i>	33%	30% <i>P=0.865</i>	56%	33% <i>P=0.110</i>



Prevention Through Peer Advocacy



Project Findings

The most important impediment to the effective treatment of HIV infected teens is the inability to test large numbers of adolescents who are at risk of infection because of their behaviors. In this report we have presented the one-year results a street-based outreach method that successfully engaged large numbers of high-risk teens.

The following elements have been shown to be key to the success of this effort:

1. appropriate identification of high risk peers who have access to other high risk teens;
2. effective training of the teen peer outreach workers;
3. appropriate on the street and post-session supervision;
4. enhanced access to free HIV counseling and testing.

The aim of this report was to examine the risk characteristics of a random sample of the teens who were contacted on the street through our peer outreach approach. The data suggest that these young people are aware of the presence of HIV in their community and that they are aware that they may easily become infected. Most of the respondents thought that they might become infected. This concern is associated with a high level of HIV testing among the group. However, in spite of their concern about HIV and their professed participation in protective sexual behaviors, this group experienced a high level of adverse outcomes of high-risk sexual behaviors. In addition, concern about HIV infection as indicated by belief that they could become HIV infected and HIV testing did not have an effect on HIV protective behaviors, nor did it decrease the prevalence of the risk outcomes which were indicative of behaviors associated with high HIV risk.

These circumstances tell us a number of things. Although adolescents indicate participation in protective behaviors they seem to be at the same risk as adolescents who do not participate in protective behaviors. In our sample the adolescents who stated that they consistently used condoms were at the same risk of STD and pregnancy as the adolescents who were inconsistent with condom use. The same finding was noted for monogamy. These findings suggest that evaluators of HIV risk need to be very circumspect in the interpretation of the value of condom use histories as indicators of reduced risk. In our experience, consistent condom use may indicate an intention which is not always realized as a result of breakage of the condom, brief lapses of purpose or a number of other factors.

Both male and female respondents had been HIV tested at high rates; however the female respondents were significantly more likely to have been HIV tested than the males. This may be related to the high rates of teenage pregnancy among the females, a condition that places them in a health care setting where the HIV test is more likely to have been done.

An additional interesting finding is the lack of a protective effect from HIV concern and HIV testing. Adolescents who were concerned about HIV and those who had been tested for HIV infection did not change their behaviors. These findings suggest a continued need for aggressive HIV testing among high-risk youth. Furthermore HIV is likely to continue to spread in our community because of the lack of effective of intervention efforts.

Prevention Through Peer Advocacy

References

¹ Ibid.

² Office of National AIDS Policy *Youth & HIV/AIDS: An American Agenda* Part III - Testing, Treatment And Care; March 1996

³ Newacheck PW, McManus MH, Gelpert J. Health Insurance Coverage of Adolescents: A Current Profile and Assessment of Trends. *Pediatrics* 1992; 90:589-96.

⁴ Cheng TL, Savageau JA, Salter AL, et al. Confidentiality in Health Care: A Survey of Knowledge, Perceptions and Attitudes Among High School Students. *JAMA* 1993; 269:1404-7.

⁵ Council on Scientific Affairs, American Medical Association. Confidential Health Services for Adolescents. *JAMA* 1993; 269:1420-4

⁶ Woods ER, Samples CL, Melchiono MW, et al. Boston HAPPENS Program. *J Adolesc Health* 1998;23S:37-48

⁷ Fuedo R, Vining-Bethea S, Shulman LC, et al. Bridgeport's Teen Outreach and Primary Services (TOPS) Project. *J Adolesc Health* 1998;23S:49-58



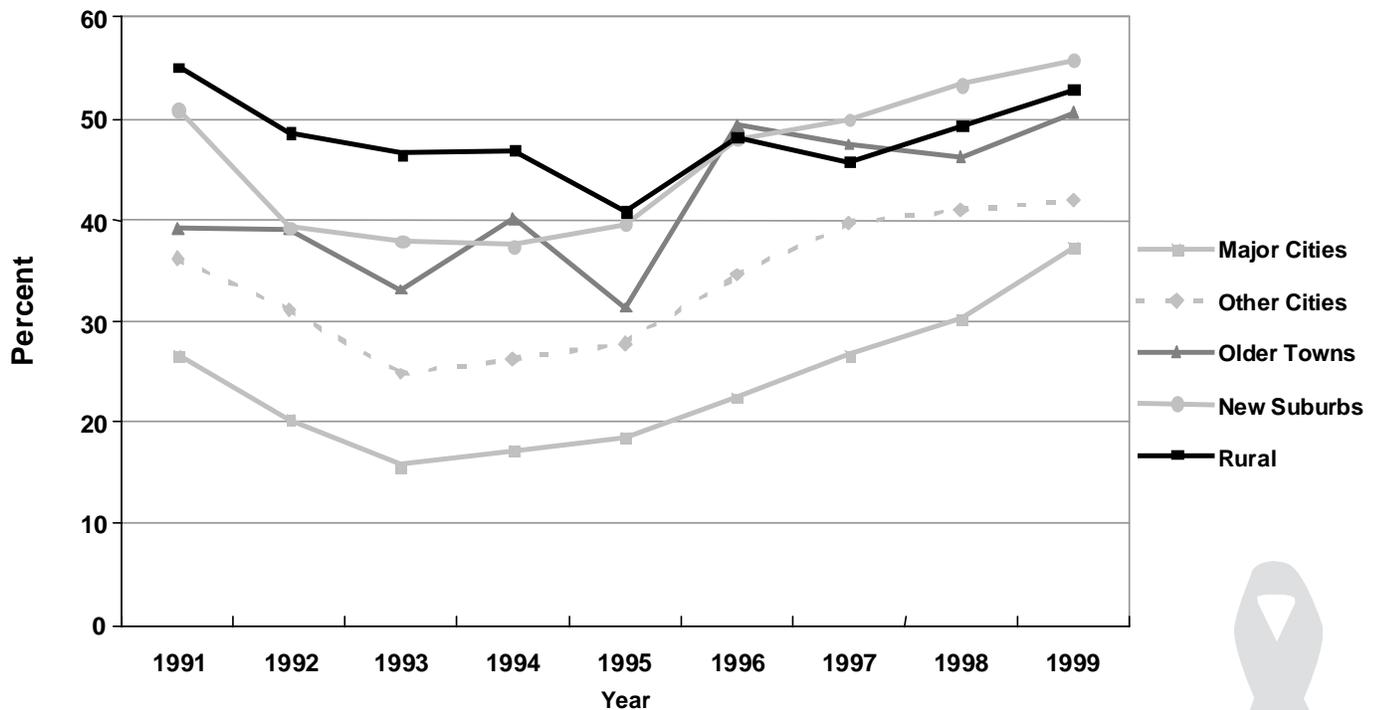
Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth

Anna Kline, Ph.D.

Director of Research and Information Systems, Division of Addiction Services, New Jersey Department of Health and Senior Services.

New Jersey collects information from about 225 treatment providers from around the state on all clients that are admitted to treatment and also data on clients as they are discharged. These data include demographic characteristics, some psychosocial information and information about their substance abuse, the kinds of drugs used, the frequency of use, and the mode of administration. Since 1980, our data show that heroin injection among people coming into treatment has dropped precipitously. In 1980, close to 100% of all heroin users coming into treatment were injectors, and by 1995, only about 30% were injecting drugs. This was true for both males and females. However, within the last few years, the injection rates no longer continued to decline, but seemed to be leveling off, and even slightly rising (see Figure 1). We looked at the data more closely to determine which population groups in particular were being most affected.

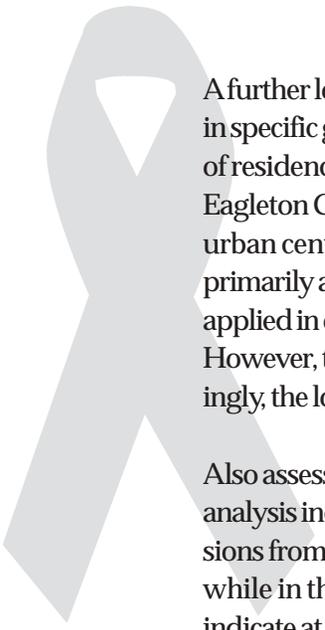
Figure 1: Proportion of 18 to 25 Year Old Heroin Admissions, Injecting by Place, 1991-1999



Injection rates are increasing primarily among heroin users in the 18 - 25-year age range. The data show a dramatic increase in this age group compared to people in the older age ranges. Between '93 and '99, the proportion injecting among 18 - 25 year olds increased from 22% to 46%.



Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth *Continued*



A further look was taken to determine if this increase was occurring statewide, or if it was occurring only in specific geographic locations. To examine geographical trends, data was analyzed by the client's place of residence, using categories developed by the Eagleton Institute of Politics at Rutgers University. The Eagleton Classification Scheme identifies five regional categories, including major urban centers, other urban centers, older towns and suburbs, new suburbs and rural areas. These categories are defined primarily according to population size, population density, and growth rate. When these categories were applied in our analysis, an increase in the proportion injecting in all regional groups statewide was found. However, the greatest proportion of injectors resided in the new suburbs and the rural areas, and, surprisingly, the lowest proportions resided in the urban areas.

Also assessed was whether there was a geographic difference in the number of heroin admissions. This analysis indicated a dramatic increase in heroin admissions from the suburbs, and a sharp drop in admissions from the cities. Thus, heroin admissions from the cities dropped from 2,018 in 1993, to 1,076 in '99, while in the suburbs, admissions increased from 691 in 1993, to almost 2,000 in 1999. The data thus indicate at least two phenomena. First, the proportion of young heroin users coming into treatment who injected was increasing statewide in all racial/ethnic groups. But secondly, both the number of heroin users and the proportion injecting was highest in the new suburban and rural communities, and lowest in the urban areas.

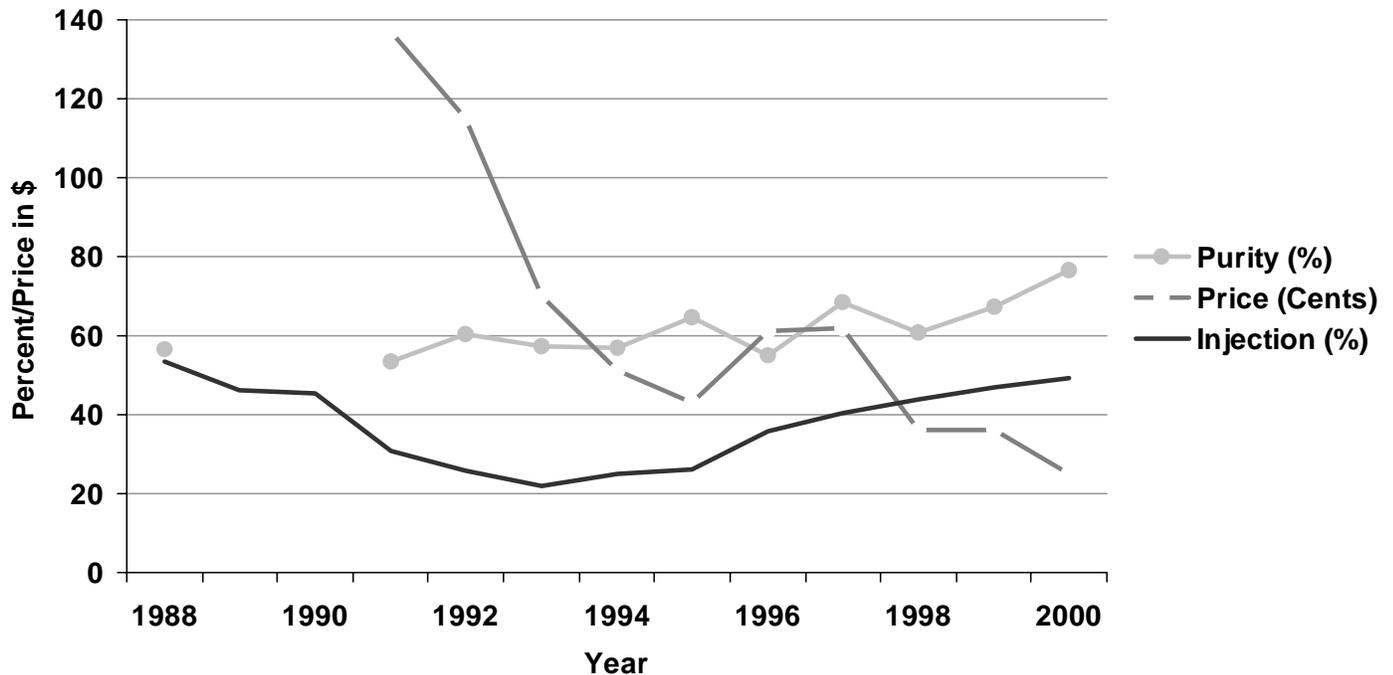
In attempting to explain the statewide increase in the proportion injecting, we examined such factors as heroin purity and price. Past research has suggested that high heroin purity and low price should actually lead to a decrease in injection, because when heroin is pure and readily available, users are able to obtain a "good" high and maintain their addictions without having to resort to injection. Our findings, however, did not support this theory. When we examined historical trends in both heroin purity and price, we found that the increase in injection occurred during the period in which the purity of heroin was at an all-time high, and the price was at an all-time low (see Figure 2). For example, in 2000, Newark had the highest purity rate of all 23 cities that were surveyed by the DEA. Purity levels rose from 55% pure in 1996 to 77% pure in 2000. This compares to an average national purity rate of about 42%. In terms of price, Newark also had the cheapest heroin of all cities surveyed. The increase in injection was thus surprising, given that current market conditions would argue against such a rise.

To further explore the problem of heroin injection in New Jersey young people, we obtained funding from the New Jersey Division of AIDS, and working in partnership with the HIV community planning group at Rutgers, carried out a small pilot study of young adult heroin users. We interviewed a total 165 heroin users between the ages of 18 - 26. One hundred and five respondents were in treatment and 60 were out of treatment. We drew our sample from seven cities to obtain statewide geographical representation: Newark, Jersey City, New Brunswick, Trenton, Atlantic City, Asbury Park and Camden. Clients in treatment were recruited primarily from methadone and residential treatment agencies in these cities.

We also tried to recruit heroin users who were not in treatment, using a combination of street outreach, and snowball techniques (asking clients in treatment to nominate friends or acquaintances who were out-of-treatment heroin users). This strategy worked well in the urban areas. However, recruiting out-of-treatment addicts in the smaller cities and suburbs was more difficult since these areas contained no

Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth *Continued*

Figure 2: Heroin Purity, Price and Proportion of 18-25 Year Olds Injecting



organized street life that could be readily accessed by outreach workers. Also, because much of the drug use in suburban areas took place in people’s homes, this population was very difficult to reach.

The interview protocol involved offering potential participants an incentive of \$15 to take part in the study. Most eligible individuals were anxious to participate, so we had very good representation among those approached about the study. Face-to-face interviews were conducted by trained interviewers with the interview taking about 30 minutes to complete.

In terms of the demographic characteristics of our sample, 52% were male and 48% were female. Most were in the 24 - 26 year age range. Forty percent were non-Hispanic white, 32% non-Hispanic black, and about 24% Hispanic. Nearly 40% had not graduated from high school. In terms of their income sources, about 60% were still receiving financial support from their parents, about 30% had obtained income from selling drugs, and 18% had exchanged sex for money or drugs in the past 12 months (See Table 1).

In terms of the geographical distribution of the sample, about 68% came from the major cities, and the remainder from the older towns, suburbs and rural areas. Nearly half of all respondents were from the northern part of the state, 22% from the central counties, and 30% from the southern counties. In terms of drug use characteristics, all were heavy heroin users. Eighty two percent were using every day, and over 40% had used heroin four times a day or more. In addition to heroin, respondents used a variety of other drugs, including marijuana, ecstasy, crack and powdered cocaine. About 60% had injected heroin in the last six months.



Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth *Continued*



Table 1: Demographic Characteristics

	%	N
Gender		
Male	52	86
Female	48	79
Age		
18-20 years-old	23	34
21-23 years-old	28	42
24-26 years-old	49	73
Race Ethnicity		
White/Non-Hispanic	40	66
African-American	32	54
Hispanic	24	40
Other	3	3
Education		
< High School	39	64
High School Grad	44	73
> High School	17	28
Income Sources, Last 12 Months		
Parents/Family	60	99
Employment	59	98
Selling Drugs	31	51
Public Assistance	24	39
Sex for Money/Drugs	18	29

Respondents tended to move from snorting to injection quickly. Over 57% of injectors had started injecting within a year of first use, and 25% had injected within six months. About 5% injected the very first time they used heroin.

We also looked at needle sources and ease of obtaining new needles. About 21% obtained their needles from a diabetic family member, and about 25% had found it somewhat or very difficult to get access to new needles.

In terms of injection-related risk behaviors, we found that many were engaged in quite risky behaviors. Sixty eight percent reported sharing cookers or cotton, 64% shared rinse water, and 55% used needles

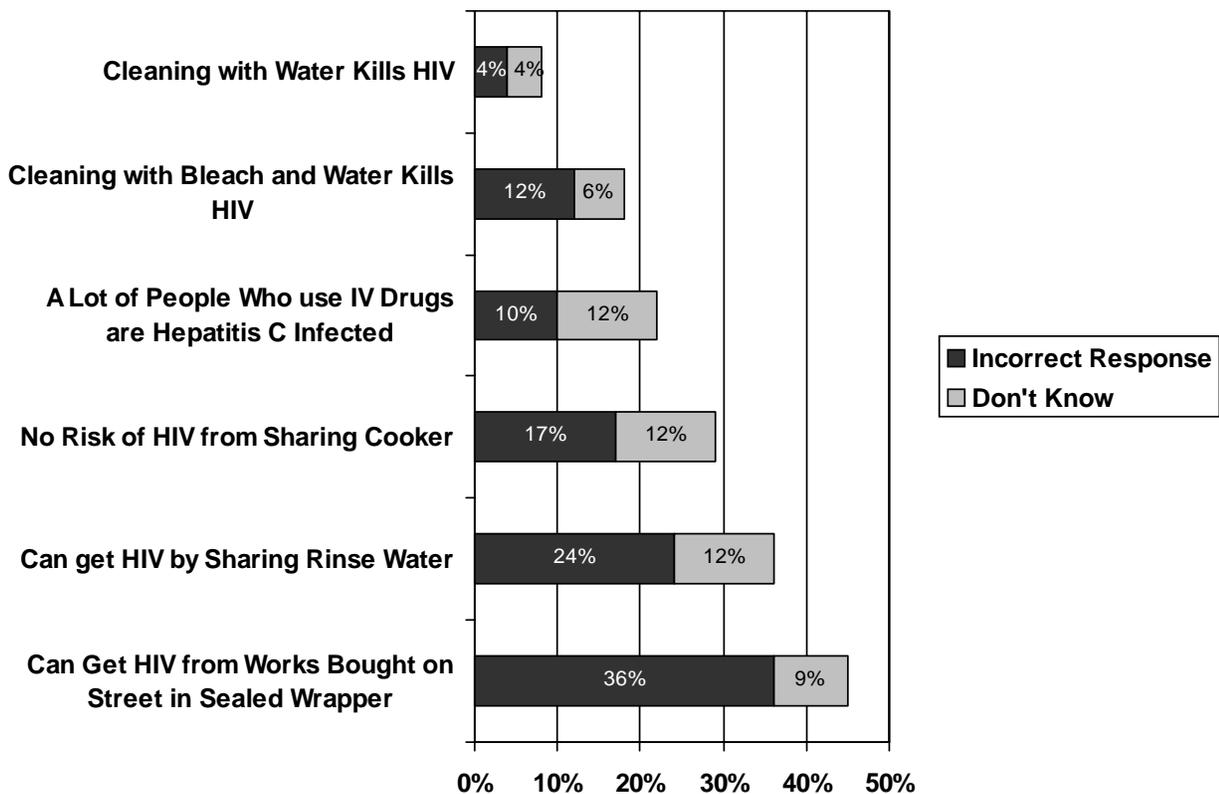
Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth *Continued*

that had been used by somebody else. However, only 11% reported cleaning their needles with bleach before injecting (see Figure 3).

We also asked respondents where they obtained most of their information about needle safety. About 40% reported obtaining information from some unreliable source, either on the street, or from relatives or friends. Also, despite the fact that about 65% were currently in treatment, only 30% had obtained information about needle safety from a drug treatment program.

We also asked respondents about their knowledge and attitudes concerning injection risks. Almost all knew that it was important to clean needles with bleach, with only 4% believing it was sufficient to clean

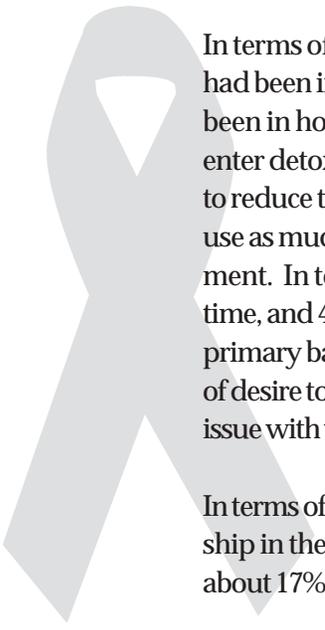
Figure 3: Percentage of Participants with “Incorrect” and “Don’t Know” Responses to Injection Risk Questions



their needles with water. However, respondents were substantially less likely to understand the risk from sharing cookers or rinse water. Twenty nine percent reported not knowing there was a risk from sharing cookers, and 36% did not understand the risks associated with sharing rinse water.



Increased Incidence of Heroin Injection and HIV Risk Among New Jersey Youth *Continued*



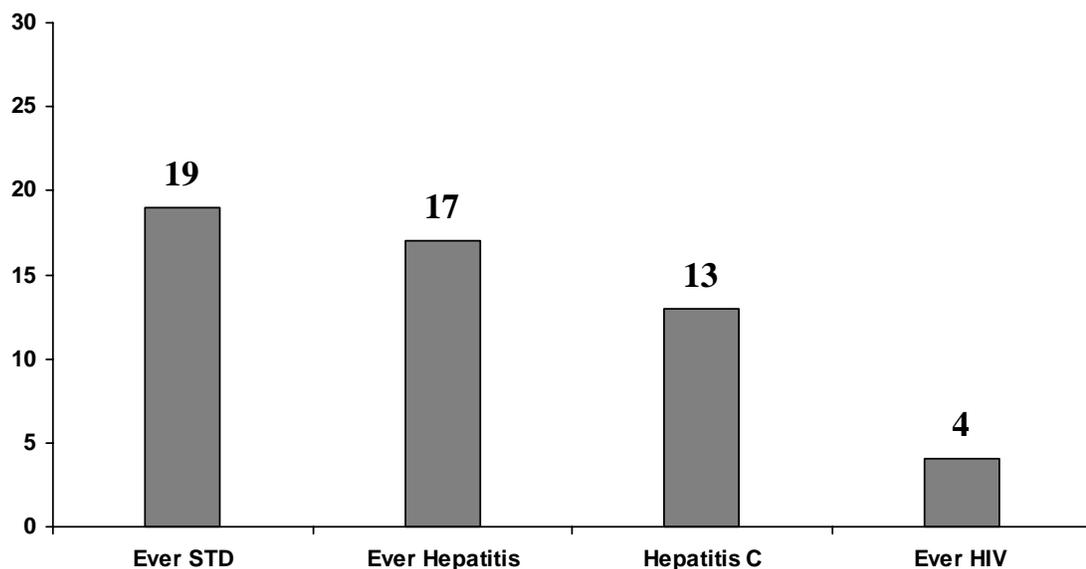
In terms of treatment characteristics, 65% of respondents were currently in treatment, and about 90% had been in treatment at some time during their lives. Of those in treatment, however, most (71%) had been in hospital detoxification. One typical pattern emerging from our treatment data is that clients enter detoxification and then fail to continue on with treatment afterwards. Many enter detoxification to reduce their level of dependency on heroin, so that when they return to the streets, they don't need to use as much heroin to get high. So, detoxification is not, by itself, considered an adequate form of treatment. In terms of other treatment modalities, about 58% had been in methadone treatment at some time, and 45% had been in residential or outpatient treatment programs. The vast majority said that the primary barriers to their entering treatment were the belief that they did not need treatment, or the lack of desire to stop using drugs. Factors related to cost or to accessibility of treatment programs were not an issue with this population.

In terms of other risk behaviors, 87% were sexually active, about 15% had been in a homosexual relationship in the last six months, and 46% had more than one partner in the last six months. However, only about 17% said they always used a condom, and 47% reported never using a condom.

We also asked questions about the effect of heroin use on their sexual behavior, since some observers believe that using heroin decreases people's levels of sexual activity. However, in this population, 44% said that sex was better when they used heroin, and 39% said that they were more, not less, sexually active after using heroin.

With respect to health status, 19% had been diagnosed with an STD and 17% had been diagnosed with hepatitis, with most of those cases being hepatitis C. Only 4% said they had tested positive for HIV, and about 90% said they had been tested for HIV, with most of those tests occurring within the last 3 - 4 years of the interview (see Figure 4).

Figure 4: Health Status



Looking at respondents' perceived risk of HIV infection, 28% felt they had no chance of contracting HIV, and 38% said that they rarely or never worry about becoming infected.

We also conducted a multivariate analysis to identify some of the factors associated with injection. In identifying variables for the model, we examined five theories frequently discussed in the literature. The first theory focuses on general risk-taking and posits an underlying risk-taking tendency inherent in the addict's personality. By this theory, injection behavior would be expected to cluster with a variety of other risk behaviors not necessarily drug related, like having multiple sex partners, not using a condom, engaging in illegal behaviors, and so on.

The social network hypothesis focuses on the role of peer influence in recruiting and socializing friends and acquaintances into the subculture of drug injection. By this hypothesis, you would expect to see similar behaviors among people of the same age group, people in the same racial ethnic groups and the same geographic regions. You would also expect that people would be more likely to inject if they had friends who were also injecting.

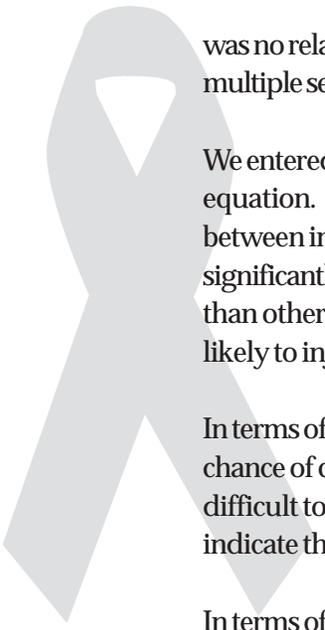
The career path hypothesis is based on the assumption that most people who begin snorting or smoking heroin will have difficulty not progressing to injection the longer they use heroin, since people develop a tolerance to heroin over time. Injection allows users to get a better high faster and to use a smaller amount of the drug in order to do so. By this theory, you would expect the probability of injection to increase as the length of heroin use increases.

The perceived risk hypothesis assumes that people will be less likely to engage in a risky behavior if they understand the risks associated with that behavior, and if they feel these risks could personally affect them. By this theory, heroin users might be less likely to inject if they felt they were personally vulnerable to HIV infection. Increased perceived vulnerability might occur among individuals who knew somebody or had somebody close to them who was infected or who had died of AIDS. Similarly, believing that a high proportion of drug users in one's community was HIV infected might increase one's sense of personal risk and prevent a switch from snorting to injecting.

And finally, the social marginalization hypothesis is based on studies of the drug culture that show that injecting is viewed as a more deviant and less socially accepted form of drug use among users themselves. By this hypothesis you would expect that heroin users would be more likely to inject if they were already socially marginalized, as indicated by such factors as being unemployed, having low education, being homeless, or incarcerated.

To test these hypotheses, we ran bivariate correlations looking at the relationship between injection and variables reflecting each hypothesis. This analysis revealed support for three of the five theories, including the social network hypothesis, perceived risk and social marginalization. Surprisingly, there was no correlation between injection and the length of a person's heroin use, which may be due to the speed in which respondents in our sample switched from snorting to injecting. Close to 60% had transitioned to injection within a year of first use, and many of those had transitioned within six months. Also, there





was no relation between injecting and other types of risk behaviors, like failing to use a condom or having multiple sex partners.

We entered all variables having a significant bivariate correlation with injecting into a logistic regression equation. With respect to social network factors, being in the same racial/ethnic group discriminated between injectors and non-injectors in the regression analysis. We found that African-Americans were significantly less likely than other racial/ethnic groups to inject, and whites were substantially more likely than other groups to inject. Also, people who had friends who injected were more than three times as likely to inject themselves.

In terms of perceived risk, injection was significantly more likely among people who felt they had a high chance of contracting HIV. This is probably because we conducted a cross-sectional analysis, making it difficult to identify the causal direction of the observed relationship. In this case, the relationship may indicate that people recognize they were at risk because they were, in fact, injecting.

In terms of the other risk variables, injection was significantly more likely if people believed they lived in communities where few of the drug users in their communities were infected with HIV. Knowing somebody who died of AIDS, however, did not seem to have a significant effect on their injection behavior.

Finally, in terms of social marginalization, there was a significant relationship with education, but again, it was in the direction opposite that expected, with the more educated respondents being more likely to inject. We did, however, find a very significant correlation between incarceration and injection, with those who were ever incarcerated being more than 5 1/2 times more likely to inject than others who were not incarcerated.

One possible explanation for this relationship is that individuals may learn deviant behaviors in prison, with a number of studies showing high rates of in-prison drug injection. In this study, we found that about 66% of respondents had been in jail or prison at some point in their lives, but only 5% reported that they had injected drugs while they were in prison. We are, thus, unsure as to how to interpret this particular finding.

To summarize, the injectors in our sample were predominantly white and had a high school education or better. They tended to associate with peers who also injected, and they tended to feel that their communities were relatively free of HIV infection, although they were likely to understand that their own risks were higher because they injected.

In terms of the policy implications of this study, the lack of interest that young people showed in treatment suggests the need for motivational counseling to enhance levels of treatment readiness in this population. Also, the fact that so few had received information about their injection risks while in treatment suggests the need to expand HIV prevention programming in addiction treatment centers. Similarly, providers should develop intervention strategies targeting young heroin users who are still snorting to try to break the transition from snorting to injection. The fact that respondents obtained

much of their information on needle safety from informal sources would argue for using street outreach to enhance the level of knowledge on the street, and perhaps encourage the formation of user networks capable of spreading more accurate information in the drug use community. Finally, it is important to address the risk of sharing cookers and rinse water, as well as needles, and to focus on sexual, as well as drug related risk reduction in this population.



Getting a Handle on Systems of Care: Access, Utilization, and Outcomes

Assessing and Improving Medicaid Care for Persons with HIV

Summarized from the presentation made by Wayne Smith, Ph.D.

Deputy Director of Finance Systems and Quality Group, Center for Medicaid and State Operations, HCFA

Over 55% of people living with AIDS are Medicaid beneficiaries, typically meaning they are disabled individuals who meet the disability requirements for Medicaid. An estimated 29% of people living with HIV infection are Medicaid beneficiaries. That means they are individuals who are typically eligible for Medicaid under one of the categorical reasons, e.g., they are typically women and are typically very poor.

HIV and AIDS care comprises only about 2% of the national Federal and State Medicaid budget. From a national perspective, this makes it very difficult to compete with the other issues that are vying for attention and the resources of the Medicaid Program. Typically, two major groups of people are Medicaid beneficiaries: mothers and children, the frail elderly, and institutionalized individuals with disabilities, for instance, people with mental retardation. Long-term care spending in Medicaid far outstrips acute care spending in Medicaid.

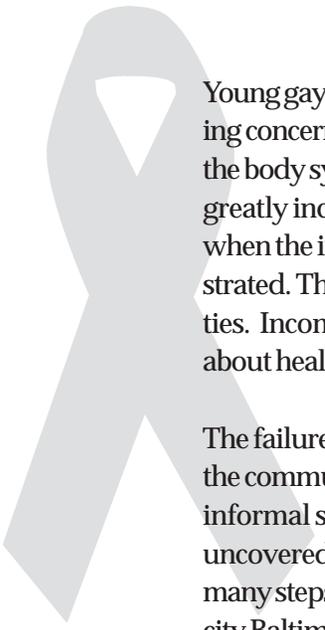
Some states, including New Jersey, have paid a great deal of attention to HIV and AIDS issues within Medicaid, but there are also many states that have not yet begun to place a strong focus on people living with HIV and AIDS.

Within public programs, Medicaid pays for about 45% of all public expenditures for HIV and AIDS care in the United States. Medicare pays for about 20% of publicly funded care for people living with HIV and AIDS in the United States. There are people who are living into the disability categories for HIV and AIDS for Medicare disability, and people who are older are becoming infected with HIV and AIDS at alarming rates. Many of these, 20%, (well over half of them) are dually enrolled in both Medicare and Medicaid, which means they are the poorest, the sickest, the most vulnerable of people living with HIV and AIDS. Today, we estimate that Medicare is now paying for more HIV and AIDS care than the Ryan White Care Act. Ryan White is paying for about 18%. Other public programs, like Housing and Urban Development, the Department of Veteran's Affairs, the Department of Defense, and others, like SAMSA, pay for the remainder of the public care. The estimated amount of public money put into HIV and AIDS care in a year is around \$10.2 billion dollars.

The trends currently observed are certainly alarming, but they are not new. What is interesting from the latest CDC evidence, is that society as a whole is beginning to learn, for the first time, how the major demographics of the epidemic have been shifting over the last 4 - 5 years. The increased incidence and prevalence in communities of color, particularly among the poor (a portion of whom are the 29% estimated who live with HIV but not AIDS, who are in Medicaid). Women, particularly women of color, are reflected in that number. Co-morbid conditions of substance abuse and mental illness, contribute to the increased alarming new trends in the epidemic. Historically, one group that has not yet been focused on are people over 50. There is now a national association of people with HIV and AIDS over 50.



Assessing and Improving Medicaid Care for Persons with HIV *Continued*



Young gay white males particularly are showing a resurgence of high-risk sexual behavior. There is growing concern about the long-term effects of combination therapies. As time goes on, more is learned about the body system's problems that result from long-term use of combination therapies. This could result in greatly increased costs of care for people who have body systems problems that were not anticipated when the initial enormously positive and important effects of combination therapy were being demonstrated. There are growing concerns about liver disease and heart problems and other kinds of difficulties. Incomplete adherence can result in resistant strains that raise costs and raise additional concerns about healthcare, which impact on public programs that serve these people.

The failure to coordinate and integrate HIV care among major payers makes it exponentially harder at the community level to coordinate and integrate care for people who are living with HIV and AIDS. An informal study of some Ryan White Care Act Title I care managers in Washington and in Baltimore uncovered some interesting findings. The principle purpose was to find out from a care manager how many steps are required in order to put together a comprehensive set of services for an individual in inner city Baltimore or the District of Columbia living with HIV or AIDS. The average was five, and it was not unusual that they had to work with seven other care managers in other programs in order to cobble together supports and services for people living with HIV and AIDS. Obviously, a direct line relationship exists between the number of units of service that had to be cobbled together and the care managers associated with them, as well as poverty and co-morbid conditions.

At the macro-funding level, the system has failed to understand the needs of coordinating and integrating care where it occurs at the care level. In turn, failure has occurred at the payment level which compounds problems and limits the opportunities for success to truly coordinate and integrate HIV care.

Some of the barriers to access, both within and outside of the payment systems, include the lack of experienced providers and practitioners. Nationwide, the variability in the availability of experienced providers and practitioners is stark. Tennessee, for example, has tried to address this problem by developing eight or nine centers of excellence throughout the state, that serve as the referral source for getting expert care. Other states are working with telemedicine, and things of that sort. The barrier that is presented by the lack of experienced providers and practitioners continues to be one of the major impediments to our ability to effectively manage the HIV and AIDS epidemic on a nationwide basis. Coupled with that is the complex problem of inadequate payment rates. Inadequate payment rates are related to not knowing how to price HIV care and this impinges upon the service delivery and the payment system. When there is a large population of people within a managed care organization, risk can be spread out over a very large number of people. The healthy people within the plan can absorb the extra costs that have to be placed into the expensive person, the person who has a high-cost disease. When there is a small base, as many Medicaid managed care plans are, especially when the base is filled with people who have high-cost chronic diseases, including HIV and AIDS, there isn't enough base to spread cost around, and loss is experienced. This can prove increasingly problematic over time. So HCFA is trying to come up with an effective model for states to use to "teach them" how to do risk-adjustment rate setting. Maryland, New Jersey, Colorado, several other states have worked, on risk adjustment, so that they can

Assessing and Improving Medicaid Care for Persons with HIV *Continued*

pay plans and plans pay providers what they think comes to what would be an adequate amount of money to provide comprehensive care for people with HIV and AIDS.

Another barrier to access is the problem of coordinating medical and social support services and needs. It is difficult for people at the local community level to put together medical and social support services, especially where one place pays for certain coverage services and another place pays for certain social-type services, and the two don't link. Additionally, there are the challenges of linking prevention and treatment services. And finally, there are ethnic and cultural challenges—the stigma issue, the fear of disclosure, that people experience within the context of high-risk behavior of HIV and AIDS, that makes it very hard, not only to find these people and bring them into care, but to keep them there and help them to be successful.

Medicaid has the opportunity, and states have the opportunity within Medicaid, to propose waivers of basic Medicaid law in order to construct programs that are targeted to the needs of particular populations, and particular characteristics of their own state Medicaid program. States have struggled with an effort to come up with a unique Medicaid HIV and AIDS waiver. One of the critical parts of an HIV Medicaid waiver is coming up with a cost model that can demonstrate that the waiver services will cost no more than their regular Medicaid program would have cost without the waiver. It's called the Principle of Budget Neutrality.

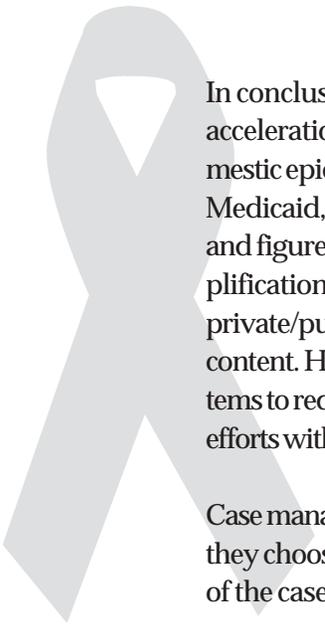
Many states are really beginning to challenge the notion that the federal government has to rethink the notion of budget neutrality; that there are reasons to have Medicaid waivers that are not necessarily tied to algorithms. In the current administration, there is an extremely important receptivity and openness to rethinking the way in which the cost aspects of waivers are done.

There are many reasons to risk adjust: for the care of chronic conditions, for disabilities, HIV and AIDS. Risk adjustment depends upon the ability to know what is currently being paid for: utilization and cost. Good data must be available before risk adjusting can be done. There is also a new emphasis on integration and coordination of prevention in treatment, as reflected in the reauthorized Care Act. There is the recognition that these are the same people we are trying to provide prevention and treatment services to. The fact that CDC is in Atlanta, and HRSA is in Rockville, should not matter in the lives of people living with HIV and AIDS. But there have been statutory funding and additional reasons why it's been very difficult to coordinate prevention in treatment plans. Add to that mix Medicaid and Medicare, and it becomes even more complex.

However, there is new emphasis across our programs on integration and coordination of services from different payment sources. Secretary Thompson recently released a statement, indicating that he wanted the department to look at ways to improve the efficiency and coordination and integration of all of the services for people living with HIV and AIDS that are funded by the Department of Health and Human Services.



Assessing and Improving Medicaid Care for Persons with HIV *Continued*



In conclusion, there is a growing fear that the domestic epidemic is on the verge of another phase of acceleration. Medicaid, as well as Medicare, will be increasingly impacted by these changes in the domestic epidemic. Dramatic changes in the demographics of the epidemic demand focused efforts within Medicaid, within each state, but also at the level, to reach out to other local, state and federal resources, and figure out how to make them work effectively and efficiently together. HIPAA, administrative simplification is federal law that states that over a two or three year period of time, all health transactions, private/public, that have a relationship to payment, must be in standard electronic format and standard content. HIPAA administrative simplification is driving states' Medicaid management information systems to redesign and upgrade. It provides a unique opportunity to focus on integration and coordination efforts with other programs.

Case management is an optional state planned service that is available to state Medicaid agencies, should they choose to use it. It requires state cost, obviously, and not many states have really taken advantage of the case management optional benefit, but it exists. It is there.

In assessing waiver mechanisms for states to address and provide case management, two states have provided interesting examples: The most prominent waiver vehicle is the Section 1115 Waiver. Most provisions of Medicaid can be waived and it would be possible to do case management quite effectively. An 1115 Waiver can be targeted for people living with HIV and AIDS (as the State of Maine, Massachusetts and the District of Columbia have done...and Georgia is in the process of doing).

Georgia has put together a Section 1115 Waiver that comes the closest to integrating Ryan White Care Act and Medicaid programs. The care management function within the 1115 Waiver in Georgia is really thought about in terms of being a Ryan White role. The enrollees in the eligibility expansion in the 1115 Waiver in Georgia are the same population as the AIDS Drug Distribution Program (ADDP) population in the State of Georgia. So they are effectively taking what Medicaid can do and pay for, and what Ryan White can do and pay for, and putting them together into an integrated care coordinated program. This shows the creativity and some of the best working relationships between Medicaid and Ryan White around a particular goal of coordinating and integrating care, minus budget neutrality.

There is an effort within the department to step way back and look at the way in which all of data systems are not coordinated and not integrated. Another interesting issue is the reporting of data that is not involved in a transaction and is not covered by HIPAA. How can administrative simplification be used to push standardization out farther than is actually required by the law for a public health purpose? Interpretations are still evolving.

HIV Care Research and Administrative Data Linkages

Summarized from the presentation made by **Lisa M. Lee, Ph.D.**
Epidemiologist, Centers for Disease Control and Prevention

Since the first epidemiologic studies of AIDS suggested sexual and needle-sharing behaviors as the conduit for infection with the virus that causes AIDS, we have been developing and implementing HIV prevention programs. Since medical and pharmaceutical progress against HIV was made, we have been developing and implementing strategies to improve HIV care and treatment. It is with both prevention and treatment improvements in mind that we strive to study what works and what does not. That is, we want evidence-based prevention programs and care and treatment protocols. Collecting and analyzing data to that end can be expensive. In the interest of economy and efficiency, many of us have been thinking about ways to use the data that are already collected, in most cases for purposes other than epidemiologic research.

First we define and provide examples of administrative data. We will then discuss the strengths and limitation of these data. Finally, we will outline ways in which administrative data can be used for HIV care research.

In this context, administrative databases are those produced for reasons other than epidemiologic research. Examples include billing or service claims (e.g., Medicaid, pharmacy, hospital discharge summary), electronic medical records, and public health surveillance registries (e.g., vital statistics, disease registries). Alone, these databases are generally inadequate for epidemiologic studies. Most often these studies require that administrative databases be linked to other data sets in order to obtain all the variables necessary to examine particular hypothesis.

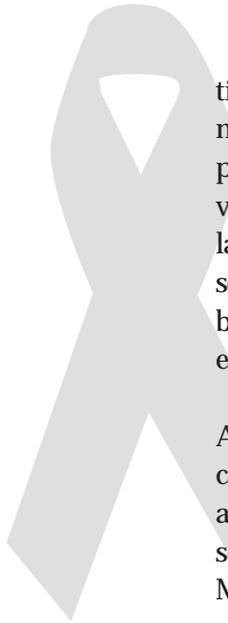
There are several things that make using administrative data helpful in our charge to make evidence-based decisions. One clear advantage is that there are large numbers of observations in administrative databases. Millions of Medicaid claims, for example, are submitted each year for reimbursement. The large number of observations means we have a high level of statistical power in our epidemiologic study, which allows us to examine small differences between groups or infrequent outcomes.

In addition, administrative databases often contain information on a more extensive population compared with studies that sample participants for inclusion. Some administrative databases can be considered population-based and provide representation of all demographic groups of interest. By definition administrative data are already collected, so study costs are reduced.

Often these data sets contain data that are not available elsewhere. From HIV/AIDS surveillance we can get case numbers, demographics, and clinical characteristics, but we do not routinely collect information on outcomes. For example, after a low CD4 count is reported for a person, we do not get informa-



HIV Care Research and Administrative Data Linkages *Continued*



tion on the clinical outcomes or the health care services that are associated with the low count. By matching a claims database or an electronic medical record to the surveillance observation, we can piece together a data set that allows us to assess many aspects of HIV care, including costs associated with certain clinical events or whether practice guidelines are being implemented. The State of Maryland was one of the first states to use Medicaid data for cost studies, as Wayne Smith [an earlier presenter] suggested this morning. The other type of information often available from administrative databases but absent in public health data sets is characteristics of healthcare providers; this allow us to examine what characteristics of providers influence care, service utilization, and many other outcomes.

Another benefit of administrative databases is that they provide us with the choice of study design. We can design case control studies, retrospective and prospective cohort studies, survival analyses—just about any study design - which means that the breadth of questions we can ask is large. Administrative data sets also offer a large, readily available comparison group. The number of people with HIV in a typical Medicaid or managed care database, for example, is relatively small. There is a large population of uninfected people from which to choose to construct a comparison group.

Finally, using administrative data can help reduce participant information bias. When using these data we are not relying on study participants to recall, for example, what medication they were on when they had their last lab tests. This is especially important if we are looking over a longer period of time; our memory serves us less well the further we are from the event. If we are interested in questions of a sensitive nature, for example history of a sexually transmitted disease, using laboratory test administrative data may help diminish misreported information.

For all their strengths, administrative databases have limitations, some of which can be addressed and others that can cripple research projects. One common limitation is that a single database may not contain data on important confounders. For example, we are working on a study using Medicaid data and looking at cervical cancer among women with HIV. We have many benefits of administrative data: a representative population, a large comparison group, a relatively rare outcome (invasive cervical cancer), and health services utilization information; but we are missing some potential confounders, such as smoking and parity. Linking with another database or performing medical record reviews on a sample of observations will be necessary to obtain these variables.

Another limitation, particularly for survival analysis, is administrative databases often contain censored observations. That is, people often enter a care database or a claims database after a diagnosis. They may also leave the database before the event of interest occurs. It is important to consider whether censoring is an issue when designing a study and planning statistical analyses.

Representativeness may be a concern with some administrative databases. This may come in the form of problems with external or internal validity. External validity is whether the enrollees in a database represent the larger population to which we are trying to infer. It is easier to trust, for example, that Medicaid is representative for poor women; however, there would be concerns about its representative-

HIV Care Research and Administrative Data Linkages *Continued*

ness for white gay men. Internal validity is whether the data for an individual represent the truth. That is, how sure can we be that a code indicating HIV really means the person has HIV? Often we would like to use variables whose quality has not been assessed. This must be considered when choosing a data set.

Another major issue which deserves a great deal of thought from one embarking on this kind of research is the coding challenges. In order to use administrative data, we have to identify health events, potential confounders, and other variables of interest. Administrative databases comprise codes representing the information we need. Some coding schemes are standardized, for example, ICD, SNOMED, LOINC, CPT, or agency-developed codes. It behooves us to work closely with the owners of the data to investigate the type and quality of coding in each dataset. Quality of coding varies dramatically by condition, facility, and code (procedure codes have a better reputation for accuracy than diagnostic codes). Several years ago I completed an analysis in which pregnancy was a variable of interest. One of the codes for delivery of a live birth was consistently used by a single institution to represent prenatal care. Initially it appeared that women were having a live birth every few months. Because of the potential for these types of problems, it is crucial to examine the data carefully.

Other coding problems can include upcoding, where diagnoses may be up-coded for better reimbursement; rule-out coding, where a suspected diagnosis may be entered into the database, and then not changed when the diagnosis is ruled out; broad category coding, where a diagnosis or procedure is coded in its broadest category eliminating the opportunity to look at more specific health events. Additionally, coding schemes change over time, which must be considered if research includes different time periods. The first HIV-specific ICD-9 codes, for example, were not being used until the 1990s and have since been modified. Finally, algorithms for identifying health events or confounders can be quite cumbersome and require a skilled computer programmer.

Finally, two additional concerns exist when using administrative data, especially claims and pharmacy data. The first is identifying an incident condition. It can be difficult to ascertain whether the first claim for an event or diagnosis represents the first occurrence or whether the observation is censored and the code represent a prevalent condition. Second, when comparing institutions or providers, risk adjustment can be challenging, as the necessary data may not be readily available.

While there are many limitations to consider when using administrative data for epidemiological research, not all will apply to every dataset and for those that do, there are often ways to overcome them. Overall, it is important that we work with our data partners to improve the quality and relevance of the data we collect. A recent example of agencies recognizing the importance of data quality and relevance is the CDC, HCFA, HRSA data sharing agreement, signed by the 3 agencies in 1998, which outlines guidance for data sharing that promotes the common goals of ensuring access to and improving quality of care for vulnerable populations. To overcome limitation for individual research projects, it is essential to carefully consider whether a particular database will meet your research needs. Assess the data limitations and consider whether they are amenable to correction. Validate coding of key variables on at



HIV Care Research and Administrative Data Linkages *Continued*



least a sample of observations. Fully disclose limitations of the database(s) and address how these might affect the study findings.

Once the strengths and limitations have been considered, we can begin the process of using administrative data for HIV care research. The basic steps in the process include:

- Identifying data source(s)
- Defining and standardizing data elements
- Defining outcomes, predictors, and confounders
- Eliminating superfluous variables and records
- Developing and implementing a linkage algorithm
- Conducting the analysis.

When identifying a potential data source, at least two things must be considered. First is assessing the presence and quality of necessary variables, including outcomes, predictors, potential confounders, and linking variables. Consider the number of observations that are missing values on key variables, a priori knowledge of validity of these key fields, and whether a validation study is possible. The second consideration is gaining access to the data source. Two necessary items here are a memorandum of agreement between the data owners and the research team and a clear outline of confidentiality protections. The CDC, HCFA, HRSA data sharing agreement I mentioned earlier has a sample memorandum of agreement, including a section on confidentiality protections.

Once data are obtained, the process continues with defining and standardizing data elements. These are data management tasks that apply to a single dataset, but can magnify problems when not addressed when using more than one data source. The first task includes standardizing variable qualities (e.g., type, length, indicator for missing value) across datasets. Sex, for example, must be coded the same across datasets or when a frequency is output, the distribution might consist of four levels (M, F, 01, 02) instead of the obvious two. The other major data management task is addressing skip patterns and missing data. A response may be blank because the skip pattern determines it so, not because the answer should be 'no' or the default category.

After standardizing the data elements, variables of interest must be defined. This entails translating variables as they exist into what is needed for the analysis. For example, there are many ICD codes that indicate HIV infection. If we need a single variable indicating a person has or does not have an HIV-related claim, we need to develop a coding net that includes all possible HIV codes and assigns 'yes' if they appear according to rules we set. Unfortunately, there are no recipes for such variables. There are many coding schemes in use, from formal published lists to those that are developed and maintained in a three-ring binder at a clerk's desk. It is essential to work closely with the owners of the data to be sure all coding schemes used in the database are covered in the coding nets you develop.

Once the raw data are converted into the analysis variables, superfluous variables and records should be eliminated. Datasets quickly become too large for efficient use on the computer. Eliminating unneces-

HIV Care Research and Administrative Data Linkages *Continued*

sary records or observations is also important for reducing the risk for linking errors when one database is matched with another.

If the analysis requires the use of 2 or more datasets, we must develop rules for linking observations across the databases. If one dataset has demographic information and another has outcome data, we must develop algorithms to connect these data into a single observation per person. The next step, developing the linkage algorithm, is the most challenging and important. It is also the most underdeveloped area in the literature on using administrative data for epidemiologic research. As with the coding nets, there is no standard recipe for developing linkage algorithms. The algorithm is dependent upon the availability and quality of variables in each dataset. Validation of how well the algorithm performs is essential.

We define a link as pairs of observations that are identified by the algorithm as belonging to the same individual. A match, on the other hand, is a pair of observations that truly belong to the same individual, or the 'truth'. A linking algorithm has 4 possible outcomes:

		<i>Truth</i>	
		Match	Non-Match
<i>Algorithm Result</i>	Proper Match: Two records truly belonging to the same person that are properly linked by the algorithm	Proper Match	False Match
	Proper Non-Match: Two records truly belonging to two different persons that are properly not linked by the algorithm	Missed Match	Proper Non-Match

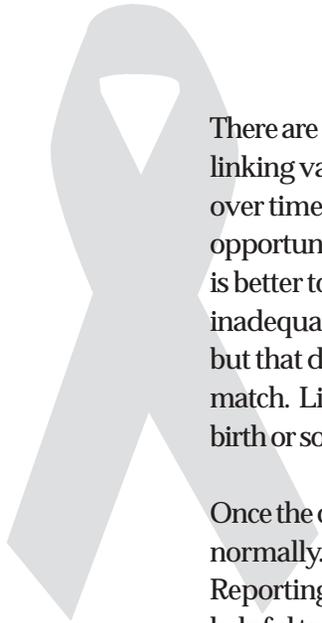
Missed Match: Two records truly belonging to the same person that failed to be linked by the algorithm

False Match: Two records truly belonging to two different persons that are falsely linked by the algorithm

The two errors that can occur are missed matches and false matches. Both types of errors factor into the performance of the linking algorithm. A validation study, using another source of data to identify the 'truth' (i.e., whether two records truly belong or do not belong to the same individual) is necessary for assessing algorithm performance. Once the validation is complete, sensitivity and specificity can be calculated. Sensitivity is the probability of the algorithm linking 2 or more records given that the records match. Specificity is the probability of the algorithm not linking 2 or more records given that the records do not match. We use these numbers to determine how much error there is in the algorithm and how much we can tolerate for a given analysis.



HIV Care Research and Administrative Data Linkages *Continued*



There are some additional considerations for linking algorithms. First, requiring perfect agreement on all linking variables will cost misses of true matches. This may be of special concern when linking records over time. Second, we must weigh, given the research question, whether it is better to have missed an opportunity to match or to have falsely matched. This depends on the research question and whether it is better to over- or underestimate our results. Third, simply counting the number of agreements is an inadequate evaluation of the algorithm. We can match all records if we make the criteria loose enough, but that does not reflect accuracy. Finally, not all agreements provide the equally strong evidence of a match. Linking the first initial of the first name does not provide as much evidence of a match as date of birth or social security number provides.

Once the cumbersome data management and linkage algorithms are completed, data analysis proceeds normally. Statistical concerns resulting from the multiple data sources should be accounted for here. Reporting the content and performance of the linkage algorithm is important. It can also be extremely helpful to perform sensitivity analysis exploring the effects of loosening or tightening the linking criteria.

In summary, administrative databases have a number of advantages for HIV care research. Limitations exist, but many can be addressed during data management and analysis. Prudent consideration of data quality and what data will be useful for answering must be given.

Improving Program Evaluation

Cultural Considerations in Prevention Practice

Felipe Gonzalez Castro, M.S.W., Ph.D. and Hector Balcazar, Ph.D.
Arizona State University

Recently the prevention intervention field has considered the incorporation of cultural factors such as ethnic health beliefs, ethnic pride enhancement, and aspects of acculturation as key components in the design of health promotion and prevention intervention programs for Latinos and other racial/ethnic populations (Hubbell, Chavez, Mishra, Magana, & Valdez, 1995; Botvin, Schinke, Epstein, & Diaz, 1994). Moreover, this emphasis on cultural aspects has built on a core assumption that traditional Latino, Native American Indian, and other racial/ethnic cultural are relational cultures, meaning that the nature and quality of interpersonal relationships is valued culturally and is of great importance in the design of intervention strategies that are culturally-relevant for many members of these special populations (Castro, Cota & Vega, 1999). Along these lines, building on the importance of interpersonal relationships for motivating and maintaining healthy behavior involves a program design that emphasizes social action in the spirit of Paulo Freire's empowerment pedagogy (Flores, Castro, & Fernandez-Esquer, 1995; Hubbell, Chavez, Mishra, Magana, & Valdez, 1995). This approach also involves the need to design programs that feature a multi-level system's approach that aims to affect not only individual behavior change, but also to effect changes in the family, and in the community.

The contemporary challenge in the design of targeted prevention intervention programs is to incorporate these cultural factors as integral components of programs, making them culturally-relevant, that is, meaningful and motivating for specific subpopulations, while also incorporating validated principles of health promotion and prevention science (Franshish, Lovato, & Shannon, 1999), and doing so in a manner that motivates, supports and maintains significant and healthy behavior change as indicated by a large programmatic effect size (Castro, Cota & Vega, 1999). In part, this approach involves one or more strategies: (1) the use of existing models and theories for health promotion, (2) the extension or these theories for use with special populations, and/or (3) the development of new theories that relate specifically to the unique needs of special populations members, especially within the acculturative context in which many members of these populations find themselves, as minorities within the larger American society (Ramirez, 1999).

Unfortunately, in the past, culturally-indifferent attitudes have existed in which cultural factors were seen as unimportant "nuisance variables," that needed to be controlled or covaried out from the intervention. Other approaches have involved assimilationist view, a "one size fits all" approach that involved changing behavior to conform to that of the dominant culture of the American mainstream. Moreover, other views have seen cultural factors as "soft" and not reflective of a "hard science" approach that is needed to guide the design and implementation of strong prevention and treatment programs. While cultural factors are sometimes subtle, and vary in importance based on the acculturative status of the targeted group of individuals, a proactive program design approach calls for the featuring of cultural factors as integral components in the assessment, intervention, and evaluation of health promotion and



Cultural Considerations in Prevention Practice *Continued*



prevention interventions that are developed to serve the needs of members of racial/ethnic and other special populations.

Within the current age of managed-care, accountability is mandated. Positive aspects of this new social service culture are the emphasis on documenting program effects and the subsequent benefits to the client. By contrast, negative aspects include the need for program evaluation expertise and data management capabilities that are often not easily available to the social service organization. Program survival requires the gathering of evaluation data. Unfortunately, programs often are administered in the applied setting without the benefits of a clear conceptualization of the process of change (mediators or behavior change), and a lack of programmatic design that sets clear specification for program evaluation. Along these lines, many times program evaluation becomes an afterthought, and in the absence of any clear evaluation design the effort is made to try to find out “whether the program worked.”

In many cases, poor or vague conceptualization regarding program components and their effects leads to an unclear understanding of how a program works to produce improvement in the client. Indeed, the question of whether the programs “works” to improve illness/problem behavior is the most basic program evaluation question. Moreover, a more important question is how the program “works,” for a given group of clients. And accordingly, how much might need to be changed to “work” for another group of clients. This requires a conceptualization of what mediators may operate that produce and may maintain healthy behavior change in the client. An extension of this would involve how cultural factors may enhance the process of behavior change.

For example, a health education program that is successful in teaching breast self-examination skills to professional English-speaking women will require modifications in program content and delivery to make it relevant for low-aculturated, low-income, low-education Spanish-speaking women. One obvious program modification for cultural relevance will be to translate the program to Spanish to make it understandable for the Spanish-speaking women. However, additional changes are likely needed to make it more culturally-relevant for these culturally-different Latino women. Here, these women differ from the original mainstream English-speaking professional women not only in terms of language, but also in terms of various culture-related variables including ethnic background, education/social class, literacy skills, etc. These differences prompt the need for changes in addition to language in order to make the program more culturally-appropriate.

Relevant changes needed would appear to involve program simplification to accommodate lower literacy, and to improve modeling effects, a health educator (a Promotora) who will be more similar in background to the women in the targeted group. These program modifications aim to address likely sources of mismatch between programmatic content and delivery and the needs of the targeted clients. A third class of changes that may be needed involve empirically-derived program modifications. This class of programmatic changes cannot be easily inferred from observed client needs, but are discovered from the empirical literature, or empirical testing of the program via focus group or pilot implementation and formative evaluation of program effects and client reactions to the program. Such empirically de-

Cultural Considerations in Prevention Practice *Continued*

rived aspects of program content and process of delivery are acquired from a well planned and implemented program evaluation, even when implemented as a formative evaluation. A “quick- turnaround” formative evaluation provides important feedback that helps to “ground” the original programs to the extant needs of the targeted group of individuals.

What are some cultural issues in program design? What is the concept of culture and how could it be incorporated into program design? From one perspective, culture involves the psychological (cognitive) aspects held in common by a large group of people based on their common racial/ethnic heritage, and based on their social interactions. This is called subjective culture, and is to be distinguished from objective culture, which refers to the external aspects of culture: the social environment, cultural products such as clothing, music, dwellings, etc. The factors that attract and retain a group of people into a defined social group create a set of group norms that define the group in terms of: mutual interests that bring members together, and a similarity in values, beliefs, attitudes, and expectations of each other. This includes mutual goals and aspects of group affiliation called group norms. Here some members may participate as core group members based on strong participation and involvement within the group, whereas others may be peripheral members based on a more limited involvement in this group. These sources of group identity and belonging create group norms that govern choice of activities, and that consist of formal or informal rules for group membership and acceptance as a member of the group. A given ethnic group consists of a cluster of sub-groups that share some aspects of culture in common, and also exhibit some variability within group as for example, in level of acculturation. A market segmentation approach to program design and evaluation (population segmentation) will clarify the identity of the target group in a field analysis and identify relevant group norms and related aspects of the subjective culture of the individuals who belong within that group.

There are several aspects regarding the “experience of ethnicity” (Castro, Proescholdbell, Abeita, & Rodriguez, 1999). One aspect involves having felt “different,” “discriminated,” or “singled out” because of ones racial/ethnic heritage. By contrast, having unique celebrations, social customs, and other life ways are also associated with ethnicity. Having a racial/ethnic identity is also based upon one’s own a self-identification and/or because other members of society identify the person as a member of a given racial/ethnic group. Here also, expressed feelings of pride or of embarrassment based upon being a member of a particular racial/ethnic peer group is also part of the experience of ethnicity. Finally, believing that one has life ways that are different from those of most Americans is also part of the experience of ethnicity. Having a sense of belonging or that one “can relate” to music or stories from that ethnic group or heritage is also a part of the experience of ethnicity. And, a desire to learn more about one’s racial/ethnic heritage is an important part of the ethnic experience.

What are some cultural aspects of program evaluation? Evaluating the effectiveness of a program/prevention intervention for meeting the needs of a specific racial/ethnic group requires attention to several issues. First, needed is a conceptual framework on a group’s program needs, and what the intervention program aims to do to improve the well-being of members of the targeted group (Frankish, Lovato, & Shannon, 1999). What are the program’s goals and objectives? What are the specific intervention



Cultural Considerations in Prevention Practice *Continued*



components (Hansen, 1992) that purport to address group needs and accomplish specific treatment/intervention goals? What are the aspects of this program (content, delivery process) that address socio-cultural needs, the cultural aspects of this intervention? What variables and measures will be used to measure program outcomes, and which of these are cultural variables and cultural outcomes?

One important aspect of culturally-relevance program design is to incorporate culturally-relevant variables into the design and intervention program (Rogler, Malgady, Costantino, & Blumenthal, 1987). These variables capture important aspects of the person's ethnic identity, experience of ethnicity, and involvement in the culture. For example the experience of ethnicity is a concept that relates to the person's life experiences based on their ethnic identity. In the process of youth development, identity undergoes many changes (Castro, Boyer, & Balcazar, 2000). Indeed amongst adolescents, identity takes many forms and is a moving target. This makes it more difficult to understand and use identity as a factor in program design. Nonetheless, for adolescents as well as for new immigrants, and for many other groups seeking to find a place in American society, identity is an important factor which must be understood and used in making programs more relevant for members of special populations.

A major challenge exists for evaluating programmatic efforts and program outcomes involving community prevention approaches designed to solve public health and substance abuse problems. In many cases, program evaluation is a concept foreign to community personnel because it is viewed as an external activity for "expert evaluators" to conduct. In listening to the voices of minority communities the sentiment is that programs that incorporate the richness of cultures as intervention strategies have the best opportunity to make an impact. The problem comes when the evaluation is not able to reconcile a clear program conceptualization within the context of a rich cultural mix that is seen in minority communities involved in prevention programs. To balance the need for a sound evaluation approach that generates value judgments based on some applicable standards that also capture the richness of the culture, new evaluation methodologies need to be developed.

In order to design a program that is culturally relevant for a specific group of people within a community, the characteristics and needs of that group must be adequately defined and assessed. Conventional program design calls for a needs assessment that examines client needs and preferences in a proposed program. A needs assessment is the ideal place to elicit and incorporate cultural content and processes into the data gathering and program planning.

In planning such a needs assessment, targeting the group of clients that would be beneficiaries of this program is an important approach. To this end, several questions can be proposed and asked. What are some sociocultural group identity questions? Does the group have a name? What brings these persons together? What do the members of the group like to do? What do they usually do as a group? What are some group goals or reasons for existing? When they are together, what are some things to do that are cool things to do? What does each group member have to do to fit in? Such questions begin to elicit the rules, whether explicit or implicit, that govern the activities of the group.

Cultural Considerations in Prevention Practice *Continued*

When evaluating program components the question arises as to what additional characteristics must be examined that can better define a peer group. For Latinos, using ecological and social action perspectives (Flores, Castro, and Fernandez-Esquer, 1995) can help define characteristics of group members who would participate in a given prevention program. Characteristics of the individual, family, and community can be used to set programmatic needs and guide the development of program components. Some key factors that define peer group classification in the context of Latinos include: level of acculturation, level of education and literacy, and family variables.

One classification approach for Latinos examines peer group characteristics based on acculturation status and family variables such as family cohesion. For example, new studies have found that peer group differences in family cohesion and acculturation are associated with different levels of smoking (Balcazar, Peterson and Krull, 1997; and Coonrod, Balcazar, et al, 1999). It is currently postulated that high family cohesiveness associated with low acculturated peer groups may function as protective factors against high-risk taking behavior.

There are scales that present the measures that can facilitate the conduct of a needs assessment for program planning, as well as aiding in the evaluation of programmatic effects. One scale measures the client's acculturation status, that is the person's orientation to the mainstream society and culture. Two other scales measure the client's enculturation status, that is, the client's orientation towards their racial/ethnic community or culture.

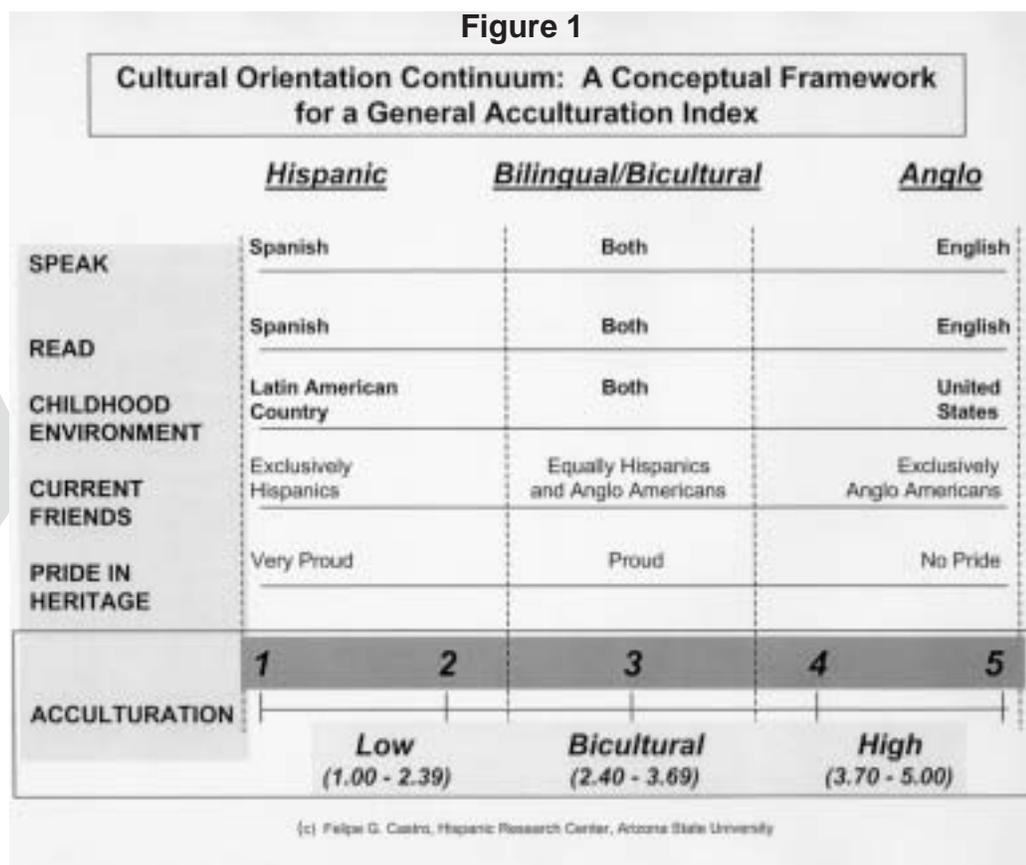
An acculturation scale measures the client's level of acculturation on a conceptual dimension ranging from high mainstream culture (high acculturation) to low mainstream culture (low acculturation). The scale presented (see Figure 1) is a condensed version of an early scale for Mexican Americans developed by Cuellar, Harris and Jasso (1980), and modified for the use in telephone survey research (Castro, 1987). This unidimensional approach has been correctly criticized for its limitations in conceptualization and use (Rogler, Cortes, & Malgady, 1991). Nonetheless, despite the over-simplification offered by this unidimensional approach to the assessment of acculturation status, many applied setting programs today still fail to incorporate aspects as basic as this basic approach as cultural content in programmatic assessment and intervention activities. For such programs, the use of this basic approach will contribute significantly towards enhancing the cultural relevance of their conceptualizations and program planning.

Two other scales measure aspects of enculturation. The Traditionalism scale examines the person's orientation towards his or her ethnic culture, while the Ethnic Pride scale measures the person's affective orientation towards his or her ethnic culture.

The concurrent use of both sets of scales can provide a composite indicator of the acculturational and enculturational orientation of the client. This acculturation/enculturation status can generate four culture orientation groups: (1) assimilation/acculturation (high in mainstream culture orientation and low in ethnic culture orientation), (2) traditional/separatist- high in ethnic culture identification and low in mainstream culture orientation, (3) bicultural- high in orientation to both the ethnic and mainstream cultures, and (4) marginalized- low identification with both the ethnic and mainstream cultures.



Cultural Considerations in Prevention Practice *Continued*



A new philosophy for designing evaluating program components includes the following elements: (1) engaging community planners and administrators as key partners and stakeholders in the decision-making process of documenting program components and their effects; (2) using a variety of evaluation tools that include experiential journeys that capture the complexity of cultures and the creativity of people involved in program components and program effects; (3) incorporating theory-driven evaluation approaches that are realistic and sound in terms or rigorous standards (CDC' Morbidity and Mortality Weekly Report, 1999).

The value of evaluation for program components and their effects in the context of cultural relevance takes into account certain premises. These are: (1) the experiential journey is captured in stories that must have a value judgments attached to them; (2) this value judgment has to be made clear; (3) assigning value means making judgments that will come from evidence that will be collected about program components and their effects; (4) in evaluation terminology these judgments are associated with three areas: merit or quality of program components, worth or cost-effectiveness of program components and significance or importance of program effects.

Cultural Considerations in Prevention Practice *Continued*

To assign value in the areas of merit, worth and significance of program components and their effects the following questions need to be answered:

- What aspects of program components and richness of culture will be considered when judging performance?
- What standards must be reached for program components and their effects to be considered successful?
- What evidence will be used from the experiential journeys and stories that will be captured in those journeys to indicate how the prevention program has performed?
- What conclusions regarding program performance and their effects are justified by comparing available evidence to selected standards?
- How will lessons learned from delivering program components be used to improve public health effectiveness in reducing substance abuse?

The following guidelines are proposed for the conduct of culturally-competent program evaluation.

1. Cultural factors should be integral components of health promotion and prevention interventions, that is, as components for assessment, intervention, and evaluation.
2. Specify the sociocultural characteristics of the targeted group by moving beyond demographic variables and looking at subjective culture variables; that is, values, beliefs, attitudes, expectations, and family system factors such as family cohesion.
3. The “experience of ethnicity,” is a daily reality for many persons who have a racial/ethnic heritage, and relevant aspects of this experience should be incorporated into programs that purport to address these persons’ the health needs.
4. Incorporate an evaluation design into the intervention at the time of program development; all health promotion and prevention intervention programs should have a clear program design that sets clear specifications for program evaluation.
5. Target a specific subgroup of clients (population segmentation) and based on their needs, design a program to meet these needs
6. Incorporate community members as key informants and as contributors to the design and evaluation of the program.
7. Incorporate story-telling narratives into the program evaluation procedures.
8. Establish a mix and balance involving the rigors of strong quantitative program evaluation design and measures, with the depth and richness or qualitative narrative approaches.



Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations

Robert Fullilove, Ed.D

Associate Dean for Community and Minority Affairs, Columbia University

HIV research can be likened to the way many linguists study how particular groups tailor the use of everyday language to express ideas, values, and concepts that are of special interest to other group members. This specialized communication is the object of discourse analysis. Among those who work in HIV/AIDS, there is a very specialized, ongoing discourse about evaluation. Within this discourse, evaluation often means more than determining what program strategies work best or assessing what impact of a particular program, intervention, or strategy has had on a group of clients.

In 2000 the Centers for Disease Control (CDC) developed a Strategic Plan for HIV Prevention for the year by convening a group of experts to discuss the most effective way to use the Centers' resources to achieve a group of very lofty prevention goals. Many of the strategies that were identified to reach these goals focus on the use of evaluation. The reasons are clear: people want to know what works. Few evaluation researchers would argue with this goal because it goes to the very heart of why impact evaluation studies are conducted.

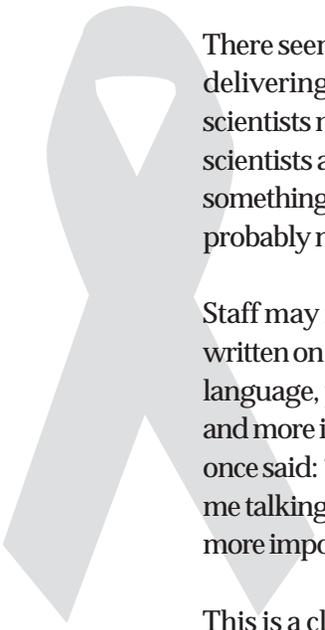
But in the evaluation discourse of AIDS professionals, interest in evaluation isn't simply in the science of identifying what succeeds and why. Many believe that there are only two types of programs, those that work—and everything else. This belief leads to some difficult interactions among colleagues who work in or manage these programs. Given the limited resources at their disposal, they worry about the programs that aren't working because they want to get rid of the deadwood — the programs that aren't doing the job — so that money and resources can flow (deservedly) to the ones that work. It is not uncommon to find researchers upset about grants awarded to others with new or unproven projects and studies, while their own experienced, successful program runs low on resources.

The point is simple. One of the by-products of this way of thinking is that evaluation has come to be viewed as a tool of reckoning, making people accountable for their failures. Evaluation is more a weapon that can be used to assess and destroy (to level the playing field?), and less a tool for improving what is being done and how it is being done.

This attitude may produce an antipathy for evaluation among staff, directors, and clients, that the evaluator may encounter the moment he or she walks through the doors of an ASO. These are natural emotions for people who worry that the evaluator's first interest is not in science but in using the tools of empirical research to do harm by 1) making everyone's job more difficult, 2) by digging into the intimate details of inter-staff and inter-client communications, and 3) by publishing data that will destroy a program and all of its good deeds.



Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations *Continued*



There seems to exist an implicit tension between people who are on the front lines day in and day out delivering the services to at-risk populations — and those who are evaluation scientists. Evaluation scientists may view themselves as truth seekers. By contrast, however, many staff perceive evaluation scientists as “outsiders” who are coming in to try and understand something that they don’t even do, something that perhaps they are incapable of doing. Since they cannot do it, the reasoning goes, they are probably not really able to fully understand the work of the ones who do.

Staff may feel that there is a special bond that they share with their clients that goes beyond what is written on the pages of a successful proposal for funding. Staff and clients alike may each speak the same language, participate in yet another special discourse that the evaluator may not be able to understand, and more importantly, may not be able to capture when an evaluation study is designed. A case manager once said: “If you don’t do the work, don’t come in here acting like you can understand it. When you see me talking to a client, do you really know what you’re seeing? Can you understand what I’m saying, or more importantly, what I’m not saying?”

This is a classic clash of cultures. Evaluators are sophisticated about statistics, numbers, logic, and science. They pride ourselves on seeing the patterns in their data. But they function within a national phobia that most Americans have about things mathematical, which is arguably one of the worst taught subjects in our schools. When program staff understand that numbers are going to be collected, primal fears may be raised. For them, nothing is more impossible than to examine complex human interactions and convert them into quantitative data. “What I do isn’t about numbers,” they may protest to the evaluators, and often, they want assurances that the evaluator understands this.

Staff want to talk about what it is like to sit down with a crack addict in the middle of Avon Avenue in Newark, New Jersey and talk to this person about getting into treatment; they know this to be a person that may only show up once every three months, whose life is in total chaos. Staff are happy that such a person is able to come in and remain in a program or a service for more than a week. And as staff members ponder the nature of a dozen other kinds of encounters that make theirs a really difficult job, they can’t help but wonder: “How does an evaluator put a number on that?” That is a good question.

As the HIV/AIDS epidemic continues, and an ever more complicated group of clients and consumers are dealt with, the challenges that evaluators face become ever more difficult. Capturing this complexity is like trying to hold water in an open palm. Worse still, most evaluation studies are under-funded. Policy makers are under significant pressures to put as much money as possible in the hands of service providers in order to meet a growing list of clients and their needs. Not surprisingly, program evaluation almost invariably takes a back seat in the face of such pressing needs. Often there is simply not enough money to design an appropriate study, and because the evaluators lack the resources, their study designs are often less than optimal.

In the face of such challenges, evaluators can only succeed if they have the full, thorough, complete cooperation of the staff. And yet, these are the very people who believe they have everything to lose and nothing to gain by assisting the evaluator to conduct a thorough assessment of their programs. Staff may

Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations *Continued*

be required to stay connected to clients as well as a source of data, which often elicits comments like: “Hey, that’s not in my job description! Show me where it’s written down that I have to help you people fill out this survey. I’ve got people to see. Places to go, things to do!” In short, what evaluators want from program staff is frequently perceived as a distraction as well as a threat to staff self-interest. Worse still, in all too many instances, evaluators come in, get the data, and then leave.

In such instances, the rapid, unannounced departure of the evaluator frequently leaves the staff with a question: “How did we do? Since we got funded this year, can anyone figure out how much of that was the evaluation, and how much of that was just being political?” If staff never get to see these reports, very legitimate questions may go unanswered. If staff members were asked to do a needs/ benefit analysis in which they were asked them to assess the value of an evaluation, most would conclude that the time spent in collecting and analyzing data is rarely worth it. It is a rare evaluation, indeed, that has the staff saying, “Oh that was great. That was wonderful. Please come back and do more!”

While the evaluators, for the most part, are just happy to finish the job without any more hostility or resentment.

There are easier jobs. The classic challenge for those who attempt to do evaluations in large ASOs is to find our way through a labyrinth of programs and services. Many organizations have a funding stream that includes grants and/or contracts with dozens of different funders. The evaluator might just be interested in an evaluation of the CDC’s component of this complex maze. But how does that CDC segment fit in with all the other services and programs clients are offered? Perhaps half of what the staff is doing involves referrals of clients to other programs and other service providers in other organizations. The evaluator may want a sample of clients to provide data on the CDC component of this chaos, but viewed up close, the client, the program, the services, and the referral are all one big moving target. Each part is indistinguishable from every other part.

There seems to be a major “disconnect” between what has been learned about the conduct of classic evaluation studies and what must be done in order to conduct an evaluation within the complex organizational maze of a typical AIDS Service Organization (ASO). The textbooks all suggest that the evaluation should be designed at the same moment that the program or intervention was designed. But the reality is that the evaluator is often called in (perhaps) three years after a program has been in operation. The evaluation is being done because the funder threatened the program with a fate worse than death unless such a study was done. However, the program is housed in a community-based organization with an old computer with a Pentium II processor, its data files have cobwebs, and when the evaluator asks, “Can I see some of your hard copy files?”, the response is all too frequently uproarious laughter.

The evaluator then asks for something simple: intake forms. The staff response? “Well you know, depending on who is paying for what, I’ve got seven different types of templates for providing information to each of my funders and/or contractors.” And then they haul out the different forms and say, “Pick or choose one.” The evaluator, undaunted and as yet and unwilling to admit defeat asks: “Well, do you think it’s possible for us to develop, er, another form to collect my data?”; the response is more laughter.



Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations *Continued*



“Oh...you want more information. Like, this isn't enough?”

AIDS program evaluations are sorely in need of a different paradigm. The models in the textbooks bear little relationship to what is typically seen in the field. This new paradigm has its roots in the belief that massive national evaluations, in which data is pooled from a group of, for example, Ryan White Programs all over the nation, are of limited utility. What is needed, instead, is to know how local community based programs and services are meeting local needs. The model should acknowledge real world limitations on time, on resources, and on staff availability in the conduct of such small-scale, local program evaluations.

The strategy that works best in many ASOs is to avoid coming in with an evaluation agenda as the first point of contact between program staff, clients, and evaluators. Ideally, during the first set of encounters, there should be no conversation about evaluation at all. It is much better (and in many instances, much easier) to spend a week or more just looking and listening, observing staff/client interactions and staff meetings. There will hopefully come a point in time when the evaluator will have passed a certain kind of threshold.

Hopefully, that point comes when staff and clients trust that the evaluator understands enough about what goes on in the course of an average day or week in the program to design a relevant, appropriate study. When staff and clients believe the evaluator knows the program, a real discourse can begin about what is and is not possible to evaluate. Evaluation designs ultimately have to be negotiable because the evaluator has to choose between what it is possible to do and what it is desirable to do. What it is possible to do with a limited evaluation budget is often entirely a function of what the staff is willing to do to assist with the collection of data. Unless the evaluation consultant is going to do all the interviews him or herself, there is no way relevant data can be collected without a critical assist from the staff. And that assist must be a willing assist; it cannot be ordered.

These recommendations may be self-evident, but they are easier said than done. The evaluator whose first meeting with program staff involves making demands on their time and energy for the purpose of conducting a study (perhaps by saying they have no choice but to comply) is doomed to failure. At best, the conduct of the study is going to be an uphill battle, and the quality of both the data and the findings is going to be questionable. I would insist that evaluation studies that are conducted with limited resources must begin with the creation of a significant degree of trust between the evaluator and the all of the stakeholders in a program.

One of the first priorities to be negotiated will be the program outcomes the evaluation will assess. What, in other words, are the most important results that staff and clients are striving to achieve? How many of these outcomes are obvious, and therefore relatively easy to measure, and how many of them involve “intangibles” or “subtleties” that are highly cherished by staff and clients but which are difficult to define or put into words? What is it possible to measure? In many instances, outcome measures fall far short of capturing the complexity of what goes on within the walls of an ASO, but staff and clients must at least trust that the evaluator is making the best possible effort to come close.

Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations *Continued*

It is often useful to ask the staff to meet amongst themselves to draw up different lists. One is a list of the problems that they see themselves confronting every day in order to meet client needs. The next lists the solutions that they develop for these problems. The lists provide the foundation for determining whether or not what the staff wants to do gets done and whether, more importantly, what gets done produces the desired outcomes.

Focus groups with clients are also extremely useful. The client point of view can be used to sharpen surveys and questionnaires, and to provide more effective measures of what clients do, what they believe, and what they perceive. Clients can each be given a draft copy of an instrument, and the evaluator can state that “I don’t want you to answer these questions as if you were being interviewed, but I do want you to tell me your opinions of what is being asked. I want to know whether or not I’ve worded things correctly. I want to know whether or not these questions make sense to you, so that if you were to be a participant in an interview, would you, as the person being interviewed, understand what it is that’s being asked? If something is unclear, give me a better way of wording it. And if it makes no sense at all, let me know so that I can drop it.”

This procedure assists in the creation of a reliable, useful instrument. It will assure that the language of each item is clear and meaningful for potential respondents. Moreover, it communicates that the evaluator values the input of clients, particularly if the wording of items is changed or omitted based on client critiques.

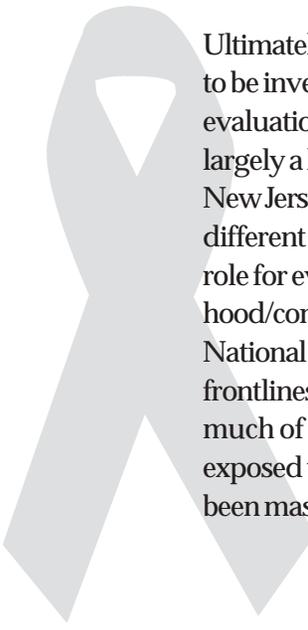
Clients and staff may speak in a language, a discourse, that is peculiar to the interactions they have with each other. Evaluators and researchers not only need to understand that language, but often need to use it to capture the most-wanted from respondents to surveys and questionnaires. These things will shift from neighborhood to neighborhood, and from program to program. Often, tuning an instrument so that the language of its questions reflects the language of the clients is one of the most important priorities in designing an effective evaluation study.

What better way of convincing collaborators of your capacity to pay attention, to hear what people are trying to say, and reflect on this input, than to present staff (and other stakeholders in the evaluation) with an instrument that accurately reflects the internal discourse between staff, clients, and administrators about the problems that must be faced and the outcomes that are the most important to measure? Moreover, the more evaluators display a willingness to “go back to the drawing board until they get it right,” the greater their chances of collecting the data that are essential for a first-class study.

This process may seem almost self-evident, it is a concern that many evaluators have a bias for standardized instruments. They will use material developed by others because of the desire to compare their results with those others gotten in evaluations of other programs. Using instruments “off the shelf” may provide us with publishable results, there is the risk of missing the essential items. The risk is run of missing the idiosyncratic nature of localized solutions to the problem of providing HIV/AIDS services to particular communities and particular groups within those communities.



Evaluations for HIV Prevention and Care and Treatment of Vulnerable Populations *Continued*



Ultimately, to improve the discourse on the evaluation of the HIV/AIDS programs, more resources need to be invested, and more time will have to be spent on the evaluation of local programs than on national evaluation studies. The HIV/AIDS pandemic, despite its prevalence in every corner of the planet, is still largely a local — and in urban America — a neighborhood phenomenon. The epidemic that we have in New Jersey — concentrated as it is among drug users and their (largely) heterosexual partners — is a very different epidemic than the one we see in rural North Carolina or in San Francisco. The most important role for evaluators of HIV/AIDS programs and services is to design well-conceived studies of neighborhood/community-based programs whose results are useful for local, as opposed to, national, audiences. National studies have their place, it goes without saying, but the real action is on the “frontlines”, and the frontlines are on the street corners, and in the local lockups, and in the bars, and in the hang-outs, where much of the HIV risk behavior is located, and where the clients of many neighborhood ASOs were exposed to HIV. The national and international epidemics will not be mastered until the local ones have been mastered. Evaluating local responses is an essential, and frequently overlooked, first step.

Summary of Individual Workgroup Discussions

Group One : AIDS Treatment Issues, Data Sources and Linkages for Treatment Research

Specific Aims

The aim of this group session was to assess HIV research needs in terms of data sources and linkages. The following were identified as areas where new data are needed:

- Estimation of accurate rates of incidence and prevalence of individuals with HIV infection
- Identification of individuals, among already infected individuals, who are not in treatment (This was considered especially important because every new infection originates from an already-infected individual.)
- Multi-faceted examination of issues related to consistent patient care at the patient, organization and provider levels
- Identification of persons with treatment failure. This was motivated by the current mortality trends in New Jersey, where specific subgroups of population (Latino and African American women) face increasing death rates.

Measuring Outcomes

The group also spent time in operationalizing measurement of some of the conceptual outcomes of interest. For example, inconsistent care was defined as lack of adherence to newer antiretroviral medications, missed physician visits and others. Again treatment failure could be measured either in terms of progressing from HIV to AIDS, or dying, which is the severest form of treatment failure.

Data Source

A lively discussion was held, contemplating whether primary data or the existing databases should be used to assist in our goal of obtaining additional data sets. Members of the group pointed out that the existing secondary data sources may be “down and dirty” and unbiased, small, primary “dream” data would be ideal to address some of our specific research questions. However, the group acknowledged that the task of primary data collection, though ideal, could be both time-intensive and cost-intensive. Because HIV infection has always been a moving target, and the best practices keep changing, the group agreed there was an urgent need for immediate results and decided to use existing data sources. Furthermore, research questions that required “dream data,” and therefore a substantial waiting period, including accurate estimations of incidence and prevalence, were dropped.



Summary of Individual Workgroup Discussions *Continued*



Available Secondary Databases

The following databases were identified as possibilities to address these specific research aims:

- AIDS Drug Assistance Program (ADAP)
- Birth and Death Certificates
- Medicaid/Medicare Claims
- Private Insurance Claims
- Title II
- UB-92 forms
- Public Use files on incarcerations

Linkages Between Databases

The consensus was that many of these research questions could be addressed only by linking several databases. Because of the inherent complexities of HIV care, many questions could not be addressed by linked, merged data alone. For example, one could use absence of laboratory reports to the State department to identify persons who are not in care. However, the absence of a lab report does not always indicate lack of care. Individuals may not have a laboratory report due to migration or incarceration. By relying on laboratory reports alone, individuals could be incorrectly classified as “not in care”. Undocumented immigrants, who may not seek treatment for fear of deportation, could also add to the complications.

In researching the question on consistent care, complex issues at the provider, organizational, and patient level need to be addressed. If consistent care is defined as adherence to antiretroviral medications, using only administrative (paid prescription and other medical care claims) would be inadequate. Administrative data can not answer the question as to whether inconsistent use is due to side effects or other reasons. Administrative data needs to be supplemented with primary data.

Solution: Collaborate, Link, Explore, Demonstrate, and Resolve

Given the complexities of HIV care, no single agency can handle the immensely complex and numerous data requirements. Collaborations, within and between state agencies, academia, service providers, and frontline data collectors are essential. Databases need to be linked, and an exploration should be made of existing data sources with limited primary data to assess the full-spectrum of HIV care. Because of the inherently complex nature of HIV care, the group suggested specific validation studies to demonstrate the ability of the agencies to move forward in addressing the research needs. The group also identified the need to resolve the inherent tension between academia and the policy makers. For example, researchers in Academia tend to spend long periods of time reviewing the issues and policy makers do not have the luxury of waiting for creative solutions.

Future Plans

The group decided that the first step toward collaboration is confidence building. In areas where new information is needed, care must be taken to gain and maintain the trust of the collaborators. This

Summary of Individual Workgroup Discussions *Continued*

includes appropriate safeguards for protection of sensitive and confidential information; not over-extending the already-burdened existing infrastructure by including unwieldy and irrelevant information during data collection. The most important next step noted by the group is to get adequate external funding to support additional efforts.

Group Two: Developing a Prevention Research Agenda

Summary

Objective: Prevent the spread of HIV

Target population: “positives”

Research issue: Mental health issues may be a major impediment to prevention efforts. However, little is known about the role of mental health in behavioral change.

Research question: Does access to mental health services increase the efficacy of prevention efforts?

Research approach: Using an experimental design, HIV+ individuals will be randomly assigned to receive standard services or enhanced mental health services.

Discussion

This session focused on the role of mental health in the prevention of HIV transmission. The chosen target population was people who are HIV “positives,” because affecting changes in risk behaviors of HIV+ individuals has a greater potential prevention impact than in non-infected individuals. Marrying treatment and prevention efforts is viewed as a particularly efficient means of stemming the spread of HIV.

Because coordinating services among facilities is a significant difficulty, members of the group believed the program would be more effective if mental health services were located in the same facility as the treatment for HIV (“one stop shopping”). The main research design discussed was a two-arm experimental design. Individuals would be randomly assigned to standard care or standard care with enhanced mental health services. Researchers could then examine if utilization of mental health services was related to behavioral change; and, if behavioral changes were sustained. In addition to examining the effects of the provision of mental health services on prevention efforts, additional analyses could explore if mental health services impacted treatment outcomes (i.e., medication compliance, and adherence to medical advice).

Another important component of the research would be to identify and quantify the types of mental disorders of individuals in the “positives” population. Describing the landscape of mental health issues would facilitate alterations in programs to better serve this target population. Furthermore, knowledge of the types of disorders would provide guidance as to the training providers should (ideally) have.



Summary of Individual Workgroup Discussions *Continued*

Because prisoners are a confined, identifiable population with high rates of mental disorders, an experimental design based in prisons may be feasible.

Issues:

- What funding sources would pay for mental health services?
- If prevention/treatment programs required (or requested) clients to fill out a mental health survey, would this constitute a significant barrier to use of prevention/treatment services?
- Existing data sources (i.e. Ryan White) are inadequate for answering the research question.
- Are there providers trained to provide quality mental health services to HIV positive individuals?

Group Three: Injection Drug Use and Youth

Objective: Identify treatment and prevention models that work with injection drug users and youth in New Jersey.

Target: Injection Drug Users and Youth

Research Issues: At-risk behaviors are on the rise as evidenced by increased injection drug use among youth of middle income backgrounds who are testing HIV. (Little is known about who they are and how to best identify or reach them with necessary health information.

Research Question: What leads to high risk behavior among youth and how can we best access this population to improve the persons participating in testing?

Discussion

This breakout group session focused on how to improve interventions through changing traditional treatment models and enhancing methods of outreach to at-risk and infected youth. As previous research in New Jersey has uncovered the increase in IDUs especially among youth and women, emphasis in the discussion was placed on how to better identify injection drug use youth not in treatment and increase the numbers of individuals that are seeking testing. A qualitative approach was suggested in assessing the high risk behaviors and impulsivity observed among the youth culture to examine what wide spread beliefs exist and external influences contribute to the increase in these behaviors. Exploration of related questions such as the effects of peers, education levels, parents, a comparison of urban versus suburban youth, race relations, and communication mediums were considered additionally important. A design technique suggested was the use of snowballing within an existing social network where youth in treatment would identify other at-risk youth who were not being tested and encourage them to do so. It was thought that places to access information about non-tested kids would be homeless shelters, soup kitchens, and “off-limit” places where only drug using youth frequent. Other methods suggested by members of the group for at-risk individual identification and quantification was the use of parents groups, suburban school boards and surveying private physicians about case reporting of positives.

Another important component of the research would be to assess the type and magnitude of these at-risk behaviors among the youth population. Compiling information from focus groups of affected youth

Summary of Individual Workgroup Discussions *Continued*

would provide an improved picture of what is the phenomena observed among youth and which risky behaviors on the rise. Further knowledge in this area would provide information on additional steps that could be taken to better address the problem, e.g.,

- Education of suburban school boards about getting the HIV message out more effectively and vigorously
- Improve the creativity of Public Service Announcements (PSAs)
- Improve other communications strategies (e.g., include a PSA about HIV in the motor vehicle handbook, enlist other communication groups in the campaign, etc.)
- Target local mental health service providers, improve prevention strategies and promote more community level education about HIV/AIDS.

Issues

- Difficulty in assessing what is leading to increased injection drug use among youth due to small numbers in treatment who may not want to participate in focus groups (e.g., what are the risky behaviors in which youth are engaged?)
- How can additional funding be earmarked for the use of communication strategies that have worked elsewhere in other markets (e.g., packaging, marketing, use of computer programs)
- Existing data sources are inadequate to identify who has access to what in the urban versus suburban youth populous and what shifts are occurring if any.
- Politicians in New Jersey have been historically opposed to needle exchange. Can the legislature be educated about the lessons of needle exchange? Can a comparison be undertaken using the Connecticut experience (a state very similar in size and population to New Jersey) to estimate the projected effect of transmission rates in New Jersey? Can the cost projection of money saved (using the money now spent on Hepatitis B and C) be used to push the advantages of this type of program?

Future Requirements

In conclusion, the group decided that a “raised” political consciousness and additional funding would be required to support further research efforts in this area. Although current data support the notion that intravenous drug use is up among youth and that a relationship exists between this activity and testing positive for HIV, little additional funding is earmarked in the state to develop prevention strategies or engage more researchers in this area. In addition, the group believed that political winds would have to change a great deal in order to begin to address controversial but successful interventions such as needle exchange. Group members supported the idea of assessing the experience with needle exchange in a comparable state such as Connecticut. The costs and benefits of the program could be determined and then offset by the costs of care associated with Hepatitis B and C cases in New Jersey. The next necessary step was acknowledged as collaboration among major groups to place pressure on policy makers to sensitize them to the issue and promote opportunities for additional support.



Overall Themes and Issues for Care and Prevention Research in New Jersey



A major focus of the meeting was the identification of ongoing research in the State as well as other areas of interest where gaps in knowledge exist. Issues such as who is being tested and receiving treatment, program and participant characteristics, system-level factors that influence service and the effects of changing demographics are some of the areas identified where additional data and knowledge are required. In addition to exploring these factors, the context in which research would be developed was discussed. Associated topics of discussion that proved equally important were the political environment within which certain subject matter could be introduced. Other considerations in the discussion included competing interests for financial resources, the target audience for the research, the potential benefits of the research, state or federal regulatory requirements, and the potential for long-term impact through improved outcomes. These and other subjects emerged as topics of discussion throughout the conference. The following section will highlight the themes and issues identified by the conference workgroups as they looked to develop recommendations for future research in their topic area.

The workgroup participants were divided into three groups and given three goals. First, the groups were to identify a research area and a target group within the HIV/AIDS population upon which to focus. Second, the group was to identify a specific research question to address and determine what resources would be required to do so and what gaps currently exist. Finally, the groups were to suggest new strategies for addressing these research agendas in the future, identify additional data requirements, determine the benefits and challenges, the effects on regulatory requirements or policy, and the anticipated cost savings realized and benefits over time.

Areas of Common Interest

Workgroup participants expressed concern about lack of adequate funding for the research activities, inconsistency in the development and use of common terms and definitions, poor data collection methods, inappropriate resources for the size of the problem to be addressed, inadequate surveillance techniques, and the need for training and technical assistance. Related topics touched upon during group discussion included the influence of race, cultural nuances, and group behavior. Many suggested various design approaches and measurement techniques to better test associations and improve proficiency in estimates. Participants also discussed the development of indicators to examine a variety of complex issues among the HIV population including providers of care at multiple levels, and treatment and prevention models.

Challenges across Research Topic Areas

Best practices in the assessment and interventions to address high risk behaviors especially among youth and the gay culture within New Jersey was identified by the groups as a major challenge. The use of better surveillance and individual identification methods coupled with appropriate techniques to pro-

Summary of Individual Workgroup Discussions *Continued*

more testing and treatment among “gay social networks” emerged as another broad-based problem. In addition, groups suggested that resources for the provision of mental health services to HIV positives be enhanced as an effective way to help stem the spread of the disease. Competing interest for health dollars in the state make the issue of finding a continued funding source for this service an additional challenge. The impetus for additional funding required linkage of existing databases to address many HIV/AIDS research questions as well as collection of supplementary primary data. Due to the complex nature of HIV, additional resources are also required for enhanced demonstrations to further explore and validate the full-spectrum of issues that compose HIV prevention, care and treatment.

Final Discussions

Final discussions of the entire group of conference participants focused on a number of various topics. First, ideas were suggested to build partnerships across organizations and agencies in New Jersey allowing participating entities the ability to exchange information and ideas. The notion that state governmental agencies are large and have multiple levels was discussed and suggestions made for the determination of a way to eliminate duplicate procedures across agencies and identify less burdensome mechanisms for clients. Extensive discussions were held around moving all governmental agency players to a more systematic manner of operations in the future.

To this end, a collaborative model operating in New York was identified. Closed meetings were actually mandated by the governor and commissioner of health within New York State. All commissioners and deputy commissioners within and across different departments are held accountable for attending these meetings, finding issues and formally identifying challenges encountered within HIV patient care. Two or three problems identified by this interdepartmental workgroup in New York State were solved by the group working together to develop a solution.

The Assistant Commissioner in the Division of AIDS Prevention and Control for the State of New Jersey concluded with remarks about the quality and quantity of information shared at the conference, the need for the attendees to reflect on the meeting experience and finally share the information gained with others who were unable to attend. Additionally, it was noted that a variety of partners within the health department will meet subsequent to this conference, sift through the conference proceedings and formulate a research agenda. Once the research agenda is clarified, the required funding budget will be developed and sources at the state, federal and private levels will be identified, approached and queried about continued support to sustain these efforts.

